

MENTAL HEALTH CRISES IN YOUTH WITH AUTISM SPECTRUM DISORDER

By

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## ABSTRACT

*Background:* Roughly 75% of youth with Autism Spectrum Disorder (ASD) have a co-occurring psychiatric disorder. These symptoms can pose a risk of injury to self or others when the child is in crisis. However, little is known about the epidemiology of mental health crises among this population. The goal of this dissertation was to fill this gap by examining mental health crises among youth with ASD from several interrelated perspectives - service use, measurement, and intervention - across three disparate studies.

*Objective:* The first study examined psychiatric emergency department (ED) use and receipt of outpatient mental health care among youth with ASD compared to two groups: youth with Attention Deficit-Hyperactivity Disorder (ADHD) and no ASD and youth without either diagnosis. The second study reported on the psychometric evaluation of the first crisis assessment measure designed specifically for youth with ASD: the Mental Health Crisis Assessment Scale (MCAS). The third study assessed one year pre-post effects of the START (Systemic, Therapeutic, Assessment, Resources, Treatment) program on caregivers' perceived support from and access to mental healthcare for their dependent, changes in the dependents' mental health symptoms, and psychiatric ED visits as well as psychiatric hospitalizations.

*Methods:* Data for the first study came from adolescents ages 12-17 years with ASD (N=46,323), ADHD and no ASD (N=408,066), and without ASD or ADHD (N=2,330,332) enrolled in the 2010-2013 MarketScan Commercial Claims Database. Psychiatric ED visits were identified when the primary diagnosis billed indicated a psychiatric disorder (ICD-9 290-319.XX).

Outpatient mental health visits were identified when a reimbursed claim was submitted by a mental health professional or a mental health-related procedure was billed during the visit. In the second study, data on the MCAS were gathered from 606 caregivers of a child with ASD, ages 3-25 years, enrolled in the Interactive Autism Network, an online autism registry. The MCAS is a 27-item caregiver report measure that asks the informant to rate the severity of 14 emotional and behavioral symptoms. The caregiver then selects the behavior they perceive as the most dangerous and rates the acuity of as well as their efficacy in managing this behavior. The MCAS was tested for internal consistency (via Cronbach's alpha), construct validity (via Exploratory and Confirmatory Factor Analyses), criterion validity (via Receiver Operator Characteristic curves, with a semi-structured clinician interview serving as the criterion variable), and convergent validity (by examining the association between the MCAS and measures of parental stress and frustration, family distress, and urgent psychiatric service use). In the third study, one year pre-post data from 111 caregivers of an individual aged 14-71 years (Mean age = 21y, SD = 11y) with an Intellectual/Developmental Disability (IDD), 58% of whom had ASD, who were newly enrolled in the START program. Perceived support from and attitudes towards the mental healthcare system were assessed via the Family Experiences Interview Schedule (FEIS). The Aberrant Behavior Checklist (ABC) assessed the presence of challenging behaviors and history of psychiatric hospitalization and ED visits for mental health purposes were gathered by the individuals' service coordinator.

*Results:* In the first study, youth with ASD had an increased rate of psychiatric ED visits compared to youth without ASD or ADHD (IRR = 9.9, 95% CI: 9.4, 10.4) and youth with ADHD only (IRR = 2.0, 95% CI: 1.9, 2.1). Youth with ASD also had increased use of

outpatient mental health services 30 days before and 30 days after the ED visit when compared to both comparison groups (all  $p < .001$ ). In the second study, the MCAS demonstrated robust psychometric characteristics, including strong internal consistency ( $\alpha = .85$ ), internal construct validity (RMSEA = .08, CFI = .97, TLI = .95), and external criterion validity (Area Under the Curve = .85). Strong positive relationships emerged between the MCAS and measures of family distress ( $r = 0.56$ ), parental stress and frustration ( $r = 0.48$ ), and use of emergency psychiatric services (OR = 24.2, 95% CI: 8.6 – 68.2; all  $p < .05$ ). Notably, forty percent of parents reported their child experienced a mental health crisis over the preceding three months. In the final study, caregivers enrolled in START reported significant improvement in caregiver service experiences (FEIS total score,  $t = 5.4$ ) and a decrease in ABC subscale scores (Hyperactivity,  $t = 6.0$ ; Irritability,  $t = 5.9$ ; Lethargy  $t = 4.9$ ), with effects sizes in the moderate range ( $d$  ranged from .7 to .6). A significant decrease in psychiatric ED use ( $z = 2.9$ ) and inpatient psychiatric hospital services ( $z = 2.6$ ) was also observed (all  $p < .001$  for Study 3).

*Conclusion:* Youth with ASD were at increased risk of visiting the ED for psychiatric purposes; however, their service use was not simply a product of decreased access to outpatient psychiatric care. Increased psychiatric ED use among this population may be due to high levels of mental health crises, which was found in the second study. Results from the psychometric analyses suggest the MCAS has the potential to identify youth with ASD at-risk for experiencing a mental health crisis and the START program holds the promise of improving outcomes, for both the caregiver and service user, while reducing dependence on costly and restrictive hospital-based services. It is hoped that the work presented here will lay the groundwork for future research on

mental health crises, with the ultimate aim of improving the lives of individuals with a developmental disability and/or serious mental illness and those who care for them.

## THESIS COMMITTEE

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## ACKNOWLEDGEMENTS

This dissertation is dedicated to my wife, Jessica Ann Kalb.

Whatever success comes from this dissertation is equally a product of Jessica's support and sacrifice as it is my efforts. My academic journey and our relationship are so intertwined that I can't help but believe the former was only possible through the latter.

Unceremoniously, I began college roughly 14 years ago. That was nearly the exact same time I met Jessica. My educational journey began by toiling through community college, with what a reviewer of my NRSA grant accurately described as "starting off with mediocre grades". Jessica, on the other hand, was a rising nurse at Johns Hopkins Pediatric Intensive Care. Jessica is bright, hardworking, patient, and absolutely dedicated to her patients and fellow nurses. I, on the other hand, was handing out fusilli and shrimp at a local restaurant. Meaning, I wasn't much of a prospect for future nuptials. Jessica somehow thought otherwise. She saw something in me that I didn't see in myself. And so we began the blissful early years of dating as I began working upwards from community college to the University of Baltimore. After completing my undergraduate thesis, an interesting bit of work on the relationship between aggression/hostility and religiosity, I proclaimed that I was PhD material. Admission committees thought otherwise as day-after-day I received 12, banal letters of rejection. Although, I am sure that the timing was simply poor. This is evidenced by the rejection letters unanimously stating that "this year's applicants were highly competitive" making it an "extremely difficult decision by the admission committee". Needless to say, Jessica endured hours of moaning as rejection letters rolled in, one after the other. She never complained and was a constant companion.

Jessica continued serving patients at Hopkins while I took a position at Sheppard Pratt Hospital. My time working on the Neuropsychiatric Inpatient Unit laid the foundation for this dissertation. I witnessed numerous tragic stories as families raising a child with autism were desperately in need and the mental health system provided little immediate relief outside of sitting in the emergency room for days awaiting a short-term stay on our unit. I shared my heartache for these families and the trials and tribulations of providing clinical care in an acute care setting with Jessica. She was able to match, even surpass, some of these stories while working in the PICU. My efforts actually paled in comparison to the back-to-back (sometimes another “-to back”) 12 hour shifts, that frequently stretched overnight, she pulled. Jessica is the hardest worker I have ever met. Even in the face of sleeplessness and sickness, Jessica rarely calls out. Her dedication is absolute.

In 2008, the most important events in my life occurred: Jessica and I were married on September 30 of that year. That means Jessica had to deal with my crazy compressed academic schedule while planning a wedding. In fact, I took my epidemiology mid-terms the day before walking across the stage. We even postponed our Honeymoon until the winter break. Her support during that year was a marvel. Financially, she took on the burden of a costly degree and new found husband who was under constant duress and without income. That is what sacrifice looks like. A highlight of that year was driving up to Boston with Jessica, despite the Connecticut traffic, to present a poster at the APA conference. During that trip I was even able to take a picture in front of the Center for the Study of World Religions, at Harvard University, where my father studied.



I finished the MHS degree in 2009. I loved the program and was proud to be affiliated with my fellow students and faculty. I subsequently took a position at the Center for Autism and Related Disorders at the Kennedy Krieger Institute. I spent the first several months face-to-face with the anguish of learning statistical programming. I wanted to quit, but drawing on my wife's determination and advice, I stuck it out. This turned out to be one of the best professional decisions I have ever made. After a year in that position, I decided I was PhD material again and this time was going to be different. I concluded that my GRE scores were the problem, so I spent our money, which was mostly hers, on GRE prep materials and three, yes three, GRE exams because my scores were subpar. They steadily improved to meeting the national average, and I thought my prestigious master's degree, previous clinical work, and cheeky humor might get me by. It didn't. Another 12 applications submitted and another 12 rejections followed. My wife was there the whole time. From driving to Ohio during the middle of the winter, and arguing about the prospect of living under lake-effect snow, to catching a flight to Georgia and eating pizza at the Mellow Mushroom, she was there for all of it: a constant companion, a trestle of support, and shelter from the storm during all of the (perhaps predestined) rejections.

At that point, enough-was-enough; it was time to settle down. On December 9, 2009 we had our Harper Grace Kalb. Harper was a fussy baby and she took us to the ends. But Jessica held down the fort, scheduling all the doctor's appointments, feeding her in the middle of the night, and pumping at work during the day. I was always impressed by Jessica's dedication to her nursing career, but that paled in comparison to her absolute devotion to being a parent. Hungry, angry, lonely, tired; none of these will stop her. Jessica never gives up, she only shows up. "Fake it till' you make it" is her slogan. Funny thing is she never fakes it – she only makes it.

In August 22, 2011, our fireball Myles Gregory Kalb arrived. A mere 21 months after Harper. He was an easy baby, but one hell of a toddler. We now were juggling “two under two” with a child care situation, which she managed, that was held together with straws and glue. And to make matters worse, I declared to Jessica that I wanted to apply for my PhD again. Yep, this is the time I thought – how could it not be? Who in their right mind would want to hear that from her husband, who was previously rejected twice, while working fulltime with two babies? After hours of lecturing about why things are different and what I have done different and blah-blah-blah, she just held my hand and said “ok honey”. Then the worst happen, I got it in. And I got in without full funding, meaning we could be left with a massive loan and no salary, from my end, for 2 years. I am not sure how many people would let their husband push the boundaries like that, but she did, knowing that she would likely have to take an unequal share of the Kalb family life while I was chasing my dreams. When I am at conferences and working late (every Thursday night), who is there to watch the kids? When I am complaining about projects and people, who is there to listen and provide sage advice (like, “Luke, don’t burn your bridges”)? I am the balloon; she is the bow *and* the rock. Without her, I would float away. The academic life can be cruel to marriages. I think god knows this and that is why he gave me Jessica.

I will conclude this acknowledgement, in the same way I opened it. Whatever benefit this work confers, Jessica deserves equal credit. Without her undying support, devotion, and absolute patience, none of this would be possible. When I look at Jeremiah 29:11, which reads “For I know the plans I have for you, declares the LORD, plans to prosper you and not to harm you,

plans to give you hope and a future”, I can’t help to think that he was speaking about her. In fact, I know he was. She gave me that scripture, which is sitting on my desk at this very moment.

I am also deeply grateful to my family for their incredible encouragement and support. My parents, Gregory and Linda Kalb, and my sister, Kesling St. Dennis, were always there, every step of the way, for the ups-and-down, the rises and falls, the successes and failures; their support never withdrawing. From late-night academic planning or unrivaled proof editing by the consummate English teach, my father, to my mother showing up at our house at 7am to watch our kids so I could attend epidemiology lectures or Keslings’ unrivaled enthusiasm (see Luke’s undergraduate convocation) that was on display as I successfully climbed each rung of the academic ladder, I am deeply grateful. My family has always let me know that my value was not placed in a degree or career; rather it was character and faith that were everlasting. I know my dedication to serving those who are castoff by society, be it individuals with a learning disability or 1 pound infants or those who have spent most of their life institutionalized, was not simply taught, but shown.

I would be absolutely remiss if I didn’t acknowledge the numerous other individuals who have played a critical role in completing this degree. First and foremost is my advisor, Dr. Elizabeth Stuart. I have known Liz for nearly a decade. I first met Liz when joining a research collaboration between KKI and JHSPH. I was immediately struck by her intellect, responsiveness to questions, and humble personality. It is rare to find someone who is brilliant, down-to-earth, and will actually respond to your emails. When I asked Liz for a graduate school recommendation, she not only replied in the affirmative, but recommended that I apply to

JHSPH. I wouldn't have applied without this suggestion. I truly believe the door to Hopkins, beginning with the DrPh and subsequently the PhD (and funding), was opened by her.

It has been an honor working under Liz. I have learned much from her. Academically, Liz has taught me a great deal about research, with an emphasis on methodology and solid study design. Her causal inference class was one of my favorites, not only for the content but her commitment to delivering instruction at the highest quality. When working with Liz, she has always provided timely and meaningful edits to manuscripts, grants, and this dissertation. She has taught me how to conduct research at the most rigorous level. While her expertise is clearly outside of my facilities, Liz always made time to engage in my area of work with enthusiasm. Just as important, Liz has taught me how to conduct myself professionally. I have never heard her speak a negative word about anyone, in the professional or personal setting, or share even the slightest personal gripe.

I am grateful and humbled to have such an extraordinary mentor. It is an honor to be part of her academic heritage, including her advisors Donald Rubin, PhD and Gary King, PhD, which dates back to William Cochran, Carl Pearson, and Sir Francis Galton. I plan to represent Liz and her lineage well. I look forward to seeking her advice and collaboration for years to come.

There are many others in my academic and professional journey that deserve recognition. At Sheppard Pratt, I would like to thank Rick Kunkel, LCSW. Rick is not only an exemplary Social Worker, but an extraordinary human being. It has been a pleasure to have him as a colleague and friend. Desmond Kaplan, MD was also a staunch supporter of mine, and I will miss catching up

with Nilda Gonzalez, MD at future IMFAR meetings. At Kennedy Krieger, I am indebted to Rebecca Landa, PhD. Her support, including numerous recommendations, has been critical to my success. I look forward to returning to CARD and working alongside her. Brian Freedman, PhD, now at University Delaware, has been a consummate friend and colleague. At JHSPH, I want to thank Peter Zandi, PhD and the PET fellows for taking me into the fold despite being a vagabond epidemiologist. In this group, special thanks goes out to Paul Nestadt, MD, Emma Stapp, PhD, Michelle Carras, PhD, Kimberly Roth, MHS, Ryan Andrews, BA and Calliope Holingue, MA. I would also like to recognize my departmental exam study members, Kimberly Roth, MHS and Jura Augustinavicius, MHS, as well as my office mates, Yuan (Marian) Tzuang, MSW and Amanda Nguyen, for sharing their humor and intellect during some of the most difficult times in this process.

I will conclude by thanking several faculty members and funding agencies. Tamar Mendelson, PhD taught me how to write at the highest level while co-authoring a Wendy Klag Application. Coleen Barry, PhD introduced me to policy analysis and was a constant supporter during my graduate studies, including be a key referee for my Wendy Klag application. Danielle Fallin, PhD was been nothing less of a champion of my academic career. She played an important role on my dissertation committee and during my recruitment phase as faculty at KKI. I know the generous package I received was due, in part, to her support. Alden Gross, PhD introduced me to the highest levels of latent variable analyses and computer programming. His intellect is only matched by his humor and grace. Without the support of Phillip Leaf, PhD and the NIMH Children's Mental Health Services grant, I likely would have not received my PhD. Dr. Leaf also pressed me to apply for my NRSA, which I likely wouldn't have submitted without his gentle

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*Cui est gloria in saecula saeculorum. Amen.*

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## **CHAPTER 1: STATEMENT OF THE PROBLEM AND SPECIFIC AIMS**

Over the last 50 years there has been a precipitous rise in the prevalence of Autism Spectrum Disorder (ASD) in the United States (US)<sup>1-3</sup>. In 2016, The Center for Disease Control and Prevention (CDC) estimates 1 in 68 children have ASD<sup>1</sup>, representing a 42 fold increase since the first epidemiologic study of autism in 1970<sup>4</sup>. This rise has important public health implications since ASD is extremely disabling. The World Health Organization (WHO) lists ASD as the 1<sup>st</sup> and 4<sup>th</sup> leading cause of psychiatrically-related disability worldwide among children under 5 and 5-14 years, respectively<sup>5</sup>.

This heavy burden of disease is partially due to high rates of psychiatric comorbidity found among youth with ASD. Roughly 75% of youth with ASD, ages 6-17 years, has at least one co-occurring psychiatric disorder and 40% of those with a single disorder also receive a second psychiatric diagnosis<sup>6-8</sup>. About half of these children exhibit aggression<sup>9,10</sup>, a third experience wandering/elopement<sup>11</sup>, and thirty percent engage in self-injurious behavior<sup>12</sup>. Detection and treatment of mental health symptoms is critical since psychopathology in individuals with ASD is severely impairing, resulting in poorer social and academic functioning<sup>13</sup> and lower overall quality of life<sup>14</sup>. Psychiatric symptoms in the child are also a robust predictor of parenting and psychological distress<sup>15</sup>, lower family well-being and functioning<sup>15</sup>, and decreased family resources (e.g., problems with employment and/or childcare)<sup>16</sup>.

Despite this significant mental health burden, there is a dearth of evidence-based mental health interventions, and providers to deliver these treatments, specifically designed for youth with

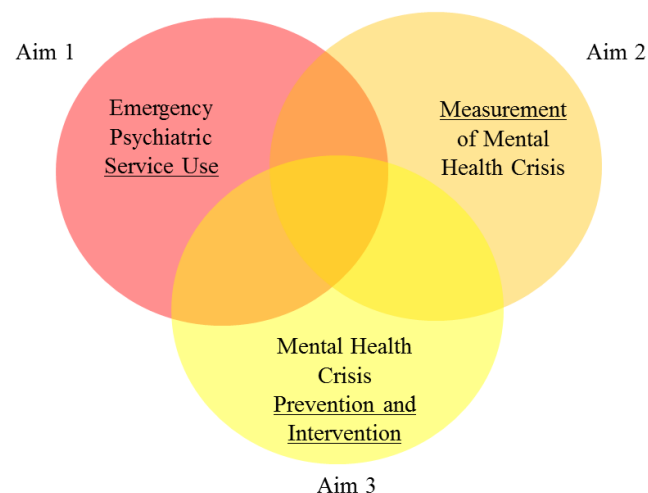
ASD<sup>17-21</sup>. This gap between need and care can place a child at increased risk for a mental health crisis, which is defined as an “acute disturbance of thought, mood, or behavior that requires immediate intervention and the resources available to safely manage the situation are not available at the time and place of the occurrence”<sup>22</sup>. The epidemiology of mental health crisis is presently unknown among all populations, as no generally accepted measure of this construct exists. One indication of a mental health crisis is use of urgent services such as visiting the Emergency Department (ED) for psychiatric care. Seeking psychiatric care in the ED is a useful analogue to mental health crises since these visits indicate that the caregiver is seeking urgent assistance to manage their dependents mental health.

Since no measure of crisis exists for the ASD population, or youth in general, the goal of Aim 1 (Study 1) is to substantiate the theory that those with ASD are indeed at increased risk for experiencing a mental health crisis by examining use the ED for psychiatric purposes. A psychiatric ED visit is a reasonable proxy for the occurrence of a mental health crisis since it involves both constructs required for crisis measurement (via the MCAS), including 1) the occurrence of a psychiatric event that requires immediate intervention and 2) the ability to management the event is beyond the caregivers capacity. More specifically, Aim 1 (Study 1) examines differences in the rate of psychiatric ED visits among youth with ASD compared to another developmentally-disabled population, youth with Attention Deficit-Hyperactivity Disorder (ADHD), and youth without ASD or ADHD. Additional goals of this study were to assess differences across diagnostic groups regarding: Aim 1a) the reason for the psychiatric ED visit, Aim 1b) access to outpatient care 30 days before and after the ED visit, Aim 1c) the probability of readmission to the ED within 30 or 90 days after the psychiatric ED visit, and Aim

1d) the proportion of ED visits that resulted in psychiatric hospitalization. Aim 2 (Study 2) addresses the existing dearth in crisis measurement by assessing the psychometric characteristics - including Aim 2a) internal consistency (reliability) and Aim 2b) construct, Aim 2c) criterion, and Aim 2d) convergent validity - of the first mental health crisis assessment scale, developed by this author alongside his team, specifically designed for those with ASD: the Mental Health Crisis Assessment Scale. The final study aim focuses on a solution to preventing and treating crises by investigating the START (Systemic, Therapeutic, Assessment, and Resources & Treatment) program. More specifically, Aim 3 (Study 3) examines one year pre-post changes in: Aim 3a) caregiver evaluation of service experiences, Aim 3b) the individual's mental health symptoms, and Aim 3c) psychiatric hospitalizations as well as ED visits for mental health purposes among a group of individuals participating in the START program.

Shown in Figure 1, this research seeks to advance understanding about mental health crises among youth with ASD from three interrelated perspectives: service use, measurement, and intervention. The dissertation consists of three papers, each

Figure 1: Tripartite Approach to Mental Health Crisis



focusing on one of the three Aims introduced previously. More specifically, Chapter 2 provides a background on the nosology and epidemiology of ASD, Chapter 3 presents the results from Aim 1 (Study 1) “Characteristics of Psychiatric Emergency Department Use among Privately Insured

Youth with Autism Spectrum Disorder”, Chapter 4 provides the findings from Aim 2 (Study 2) “Psychometric Evaluation of the Mental Health Crisis Assessment Scale” among Youth with Autism Spectrum Disorder”, Chapter 5 delivers the conclusions from Aim 3 (Study 3) “Improvement in Mental Health Outcomes and Caregiver Service Experiences Associated with the START Program”, and Chapter 6 includes a summary and synthesis of this entire body of research. The ultimate goal of this work is to reduce the burden of mental health problems among youth with ASD and improve the well-being of these individuals and those who care for them.

## CHAPTER 2: BACKGROUND

### 2.1 History and Nosology of ASD

The earliest published account of autism was detailed in 1943 by Dr. Leo Kanner at the Johns Hopkins University Henry Phipps Psychiatric Clinic. In *Autism Disturbances of Affective Conduct*<sup>23</sup>, Dr. Kanner described 11 children who were markedly similar in terms of their lack of social reciprocity, the hallmark characteristic of autism. Kanner states, “The outstanding pathognomonic, fundamental disorder is the children’s inability to relate themselves in the ordinary way to people and situations from the beginning of life”<sup>23</sup>. In this seminal paper, Dr. Kanner also identified two other key behaviors that are core to ASD. This included repetitive and stereotyped behaviors, as illustrated by Dr. Kanner’s first case (Donald) who had “a mania for spinning blocks and pans and other round objects”, and difficulty with receptive and expressive language, such as Donald’s “echolalia” and that “words to him had a specifically literal, inflexible meaning”<sup>23</sup>. Just one year later across the globe another physician, Dr. Hans Asperger of Austria, described 4 boys with similar social and stereotypic deficits as those identified by Dr. Kanner<sup>3</sup>.

Since the inaugural reports by Drs. Kanner and Asperger detailing children with “autistic disturbances of affective contact”<sup>23</sup> and “autistic psychopathology”<sup>3</sup>, respectively, the nosology of autism has changed considerably. Autism was first formally classified as “infantile autism” in the 3<sup>rd</sup> edition of the American Psychiatric Association’s *Diagnostic and Statistical Manual (DSM)*<sup>24</sup> alongside childhood schizophrenia, a condition previously considered to be etiologically related and phenotypically similar to autism. The five criteria used to define autism in DSM-III included early onset (criteria a), social deficits (criteria b), language perturbations



(criteria c), and stereotypic behaviors (criteria d and e)<sup>24</sup>. In DSM-IV, the narrowly defined infantile autism was replaced with a broader set of conditions termed Pervasive Developmental Disorders (PDD)<sup>25</sup>. These syndromes retained similarities in the core deficits of autism (language, social relatedness, and stereotypies) and childhood onset, but were unique in terms of clinical presentation and course. The DSM-IV diagnoses under PDD included Autistic Disorder, Rett syndrome, Childhood Disintegrative Disorder, Asperger's Disorder, and PDD-NOS. Except for Rett syndrome, which was dropped from DSM-V after the molecular etiology was identified, all of these diagnoses were removed from DSM-V due to concerns about lack of validity and temporal stability<sup>25-27</sup>.

Today, autism is classified and colloquially spoken of as “ASD”. Even 70 years later, criteria for ASD in DSM-V echoes what was originally described by Kanner. To receive a diagnosis of ASD, a child must display an early onset of deficits in “social-emotional reciprocity” and present with at least two of the following symptoms: 1) stereotyped use of objects, 2) inflexibility or insistence on sameness, 3) highly fixated interests, and 4) sensory abnormalities<sup>27</sup>. The fifth edition of the DSM also subsumed previous diagnostic criteria (e.g., speech language difficulties) and even specific diagnoses (e.g., Asperger's disorder) under a special section on specifiers where clinicians can utilize these terms to characterize the child's developmental needs<sup>27</sup>.

DSM-V also represents a paradigm shift in terms of how ASD is conceptualized. The 3<sup>rd</sup> and 4<sup>th</sup> editions of DSM promoted a tripartite model consisting of social, communicative, and stereotypic problems<sup>28</sup>. However, research suggested the social and communication domains are

intimately tied together and ASD is better represented as two factors: 1) social-communicative deficits and 2) the presence of restricted, stereotypic behaviors<sup>28</sup>. The reduction of conceptual domains, omission of diagnostic sub classifications, and inclusion of specifiers all highlight the goal of DSM-IV: to emphasize the dimensional nature of ASD. This shifting nosological landscape is just one explanation for the exponential increase in ASD prevalence estimates over the last 50 years.

## 2.2 Epidemiology of ASD

In 1967, Dr. Victor Lotter conducted the first epidemiologic study of autism. Data for his study were from a screening of over 78,000 children, 8-10 years of age, living in Middlesex, United Kingdom<sup>4</sup>. Using Creak's (1967) criteria of childhood psychosis, a term that autism was designated under in the pre-DSM-IV era, 135 children were identified as at risk for developmental abnormalities<sup>4</sup>. From this sample Dr. Lotter identified 32 children with autism, resulting in a prevalence of 4.5 per 10,000 children<sup>4</sup>. The first US epidemiologic study in Madison, WI - conducted by Dr. Darold Treffert in 1970 - produced a very similar prevalence estimate of 3 per 10,000 children<sup>29</sup>. Results from the UCLA-Utah Epidemiologic study suggested the prevalence of autism remained unchanged in the US, between 1970 and 1989, at 3-4 per 10,000 children<sup>30</sup>.

Since the inception of DSM-IV in the mid-90s, the US and developed countries across the world have witnessed a precipitous rise in ASD prevalence estimates. Studies published in the UK and US between 2001 and 2003 reported prevalence estimates at 30-60 per 10,000 children, representing a 10-20 fold increase compared to their earlier counterparts<sup>2,5,31</sup>. Similar increases

have been reported in developed countries, including those in the Nordic regions, the South Pacific, Asia (including Japan and South Korea), and Europe<sup>5</sup>. There is less research, and thus less evidence of an increase, among under developed countries such as those in South America, South East Asia, and Africa<sup>5</sup>.

In response to the public concern regarding the “autism epidemic” in the US, the CDC established the Autism and Developmental Disabilities Monitoring (ADDM) to track national trends across the US<sup>31</sup>. The first report, in 2002, from the CDC’s ADDM found 1 in 150 children met criteria for ASD<sup>31</sup>. Prevalence estimates increased to 1 in 110 children<sup>31</sup> in 2009 and 1 in 68 in 2014, with the latter representing a 123% increase since 2002<sup>1</sup>. In 2016, the estimate of 1 in 68 held firm as the CDC reported no change in autism prevalence estimates for the first time since beginning ASD surveillance<sup>32</sup>.

These prevalence rates are not without controversy and uncertainty, however. In a 2014 editorial in the journal *Autism*, Mandell and Lecavalier (2015) took aim at the ADDM figures<sup>33</sup>. They argued that the cost-saving approach of diagnostic chart reviews, opposed to face-to-face assessments, is highly susceptible to increased public awareness. This could severely overinflate the figures if clinicians and parents increasingly reported ASD-related symptoms, despite the child not actually meeting diagnostic criteria, since ASD symptoms are often observed in other neurodevelopmental conditions. They cite the large site-to-site variability in prevalence estimates, ranging from 2.1% in New Jersey to .46% in Alabama, as evidence that sociological, not etiological, factors are indeed at play. While there is merit to their argument, it is possible that the ADDM methodology actually underestimates, not overestimates, the true prevalence.

This is supported by the most comprehensive epidemiological study undertaken on the topic by Kim (2011) in Seoul, South Korea<sup>34</sup>. There were two notable features of this study that are superior to the ADDM methodology. First, they used a 2-stage sampling design by screening children in high-risk (e.g., special education classrooms) and low-risk (i.e., general population) settings. Second, the authors used gold standard assessments to assess the children. Results from this study placed the point prevalence at 2.64% (95% CI = 1.91 – 3.37), a rate nearly double that put forth by the CDC. Perhaps most striking about this study is the fact that 75% of the cases were previously without a diagnosis and without treatment, and would have never been detected if only high probability settings, like those employed in the ADDM, were used.

These data ultimately beg the question: What is responsible for the increased prevalence? It is generally accepted that increased awareness and recognition among parents and providers is an important explanation for temporal trends, alongside loosening of diagnostic criteria. A recent total population study in Denmark attempted to undertake the difficult task of delineating the effects of increased awareness and changes in diagnostic criteria<sup>35</sup>. Their results suggest changes in outpatient provider reporting independently accounted for 42% of the observed increased prevalence, whereas changes in diagnostic criteria accounted for 33%. Their joint effects explained 60% of the increased prevalence observed in Denmark, which supports similar prevalence estimates as the US, leaving slightly less than half of the increase unexplained.

A great deal of effort has been made to better understand what is responsible for the ASD epidemic outside of the aforementioned sociological factors. In general, ASD is known to be a highly heritable condition with a polygenic and epistatic genetic profile<sup>36</sup>. Meaning, the genetic

architecture of autism is complex and the phenotype arises from the interplay of multiple genes that are both de novo and inherited. Recent estimates place the common sense heritability at 50-60%, leaving roughly half of the disorder unexplained and presumably due to environmental factors<sup>37</sup>. It is the environmental factors and their effects on gene expression that are implicated in the increased prevalence.

Many environmental factors have been implicated in causing ASD. These include both maternal and paternal advanced reproductive age, obstetric factors (e.g., cesarean birth, low birth weight and Apgar scores), and exposure to teratogens (e.g., air pollutants, pesticides, and neuroleptics, particularly Valproic acid) as well as viral agents (e.g., rubella) during the gestational period<sup>36,38</sup>. While research has shown that environmental factors are neither necessary nor sufficient in the cause of autism, the unquestionable reality is more children are being diagnosed, and require treatment, both in the US and abroad.

### 2.3 Natural History and Diagnosis

Until the last ten years, children with ASD were often detected and diagnosed when they entered the school system<sup>36,38</sup>. However, a landslide of early detection studies has now armed clinicians with the tools to reliably detect autism as early as 18 months of age. Subtle abnormalities in eye contact and gross motor development, such as head lag, may even be present as early as 6 months of age<sup>39,40</sup>. Detection of ASD is often contingent on the developmental profile of the child, such that those with greater speech-language delays, more pronounced delays in joint attention, and loss of developed skills (also called developmental regression) may have an earlier detection of their ASD. Unfortunately, socio-economic factors also play a role, as Mandell and

colleagues (2002) found blacks were diagnosed 3 years later than whites<sup>41</sup>. Underreporting and lack of detection of ASD symptoms have also been historically found among Hispanics<sup>42</sup>. Delayed diagnosis among both of these ethnic minorities is thought to be due to poor access to healthcare, lack of education on early development, and cultural differences in terms of help seeking and trust of the medical system<sup>42</sup>.

As reflected in the term autism spectrum, disease course, symptom severity, and outcomes of children with ASD is highly variable. The strongest predictors of outcomes often relates to the child's developmental profile, including cognitive and language abilities<sup>43</sup>. Historically, development among children with ASD was broadly considered to fall into 2 classes: 1) those with mild early delays who often receive a diagnosis in later childhood and 2) and children with detectable, early delays who suffer from a static and severe course<sup>39</sup>. However, recent evidence suggests ASD onset may be marked by a series of regressions and plateaus, and thus more complex than a simple dichotomy<sup>39</sup>. Much research has been conducted on developmental regression, a phenomenon where children lose previously acquired developmental skills around 18 months to 2 years of age. Regression among children with ASD is common, at around 30% of children, which is consistently reported across studies, and is more specific to ASD than other developmental conditions<sup>44</sup>. However, how regression affects developmental trajectory is controversial and findings are highly inconsistent<sup>44</sup>. In fact, the literature is quite split with approximately half supporting no difference in outcomes and the other half suggesting a more affected profile among these children<sup>44</sup>. The *raison d'être* for this early developmental research is the hope for early detection and diagnosis, ultimately leading to early intervention that improves later outcomes.

At present, no biomarker or biological test is available for autism. This relegates diagnosis to the evaluation of a behavioral phenotype. Two gold standard measures exist for diagnostic purposes. The first is the Autism Diagnostic Observation schedule (ADOS)<sup>45</sup>, a standardized, semi-structured play-based assessment. There are 5 different modules of the ADOS, ranging from the ADOS-G for toddlers to ADOS-4 for late adolescents and adults with fluent language abilities. The ADOS is often employed by a clinician, such as speech-language pathologist or psychologist, and boasts very strong psychometric properties<sup>46</sup>. The second gold standard measure is the Autism Diagnostic Interview-Revised (ADI-R)<sup>47</sup>. The ADI-R is a structured parent report instrument conducted by a trained professional. The interview often takes 1-2 hours and covers the child's entire history of development. Similar to the ADOS, the ADI-R covers the three major symptom domains of ASD - communication, sociality, and repetitive behaviors - across 93 items. Established algorithms and cutoff scores for both the ADI-R and ADOS exist and are well-validated<sup>47</sup>. Notably, both the ADI and ADOS are based on the DSM-IV conception of ASD and have yet to be adapted to the DSM-V criteria. Given the complementary nature of clinician observation (via the ADOS) and developmental history (via the ADI-R), it is recommended that diagnostic teams and research studies employ both measures to accurately detect ASD. It should be noted that neither the ADOS nor ADI can produce a diagnosis; they are meant to inform clinical decision, which can only be designated by a physician or psychologist.

## 2.4 Burden of Disease and Comorbidities

In 2010, ASD was listed as the 1<sup>st</sup> and 4<sup>th</sup> leading cause of psychiatrically-related disability worldwide among children under 5 and 5-14 years<sup>5</sup>, respectively. ASD represented greater Total

Disability Adjusted Years (DALYs) than ADHD and Conduct Disorder combined<sup>5</sup>. This force of morbidity is the product of the early onset of ASD coupled with an often static and impairing course that is accompanied by a host of psychiatric comorbidities.

Even in the first report of ASD, Dr. Kanner observed a number of physical problems, such as gastrointestinal symptoms, among his patients with ASD<sup>23</sup>. Since that report, a large and ever expanding body of work has shown children with ASD suffer from high rates of neurological, physiological, and psychiatric problems. These rates are so high that Atladottir (2012) found an increased probability of hospital contact for 15 of the 16 ICD-9 categories of disease for children with ASD, compared to those without ASD, using a total population sample in Denmark<sup>48</sup>.

Children with ASD suffer from a host of physiological and neurological problems. Roughly half of this population has an intellectual disability and about 10% of the disorder is attributable to genetic (e.g., Fragile X, Rett's Syndrome), metabolic, or neurological conditions<sup>36,38</sup>. The three most pressing and prevalent physical conditions in ASD include: 1) seizure disorders, which occur in roughly a third of the population and has been linked to early mortality among this group; 2) gastrointestinal problems, which seems to occur in at least half of the population; and, 3) sleep disorders, which range from 40%-80% of the population<sup>36,38</sup>. Metabolic syndromes, hormonal dysregulation, eczema and skin allergies, and headaches are often associated with ASD as well<sup>36,38</sup>.

Numerous studies document that individuals with ASD have extremely high rates of psychiatric disorders, including both internalizing and externalizing disorders<sup>6-8,36,49-51</sup>. Methodological



differences between studies and the fact that no standardized measure of psychiatric symptoms has been validated in ASD make it difficult to pinpoint exact prevalence rates. Nevertheless, rates as low as 63% and as high as 96%, for a single disorder, have been reported<sup>49,51</sup>. In a clinic-referred sample, Joshi and colleagues (2010) found over 90% of youth with ASD had 3 or more psychiatric disorders<sup>8</sup>. Taken together, it is clear that externalizing (e.g., aggression, disruptive behavior) and internalizing (e.g., anxiety, depression) problems are elevated among children with ASD compared to typically-developing children as well as those with special healthcare needs (e.g., intellectual disability)<sup>52,53</sup>.

Psychopathology in this population is also persistent. For instance, Simonoff et al. (2013) found both externalizing and internalizing disorders were stable between 12 and 16 years of age among a population-based cohort<sup>54</sup>. Maintenance of psychopathology has also been reported in single subject<sup>55</sup>, preschool<sup>56</sup>, geriatric<sup>57</sup>, and other population-based samples<sup>57</sup>. Psychopathology in individuals with ASD is also severely impairing and results in poorer social and academic functioning<sup>13</sup>, and lower overall quality of life<sup>14</sup>. Psychiatric symptoms in the child are also a robust predictor of parenting and psychological distress<sup>15</sup>, lower family well-being and functioning<sup>15</sup>, and decreased family resources (e.g., problems with employment and/or childcare)<sup>16</sup>.

## 2.5 Impact of ASD on the family

Numerous studies have demonstrated that raising a child with ASD has a tremendous impact on the well-being of the family. Higher levels of stress as well as poorer physical and mental well-being have been repeatedly found among both mothers and fathers raising a child with ASD

compared to parents of typically-developing children and parents raising a child with other special healthcare needs, including those with an intellectual disability or a chronic health condition<sup>58,59</sup>.

Mothers appear to be particularly affected, with high levels of emotional and psychological distress, by raising a child with ASD<sup>60,61</sup>. One explanation for such is these parents tend to report high levels of social isolation<sup>62</sup>, lower quality of interpersonal relationships<sup>63</sup>, and decreased marital satisfaction<sup>64</sup>. Unfortunately, to deal with such high levels of stress, these fathers often reportedly cope by becoming less involved and distancing themselves from their family<sup>65</sup>, making the situation that much more difficult for the family.

Poor social relationships, mental health problems, and increased stress among both the father and mother may be due, in part, to their own autism spectrum symptoms. Numerous studies have shown that non-clinical levels of social aloofness, restricted interests, and pragmatic language styles are elevated among these parents. This syndrome is termed the broader autism phenotype (BAP) and represents a genetic liability for ASD in the family member. A recent study by Ingersoll (2013) found BAP symptoms were indeed associated with depression, maladaptive coping strategies, less social support, and higher levels of stress<sup>66</sup>. BAP symptoms, as well as ASD, are also increased among siblings of children with ASD. However, the effects of having a sibling with ASD, among non-affected siblings, are inconsistent and require further elucidation<sup>67</sup>.

Raising a child with ASD also has a detrimental impact of the parent's career. Parents of this population report decreased employment hours and a perceived inability to seek advancement in

their career. Perhaps the most comprehensive study to date on the topic comes from Cidav (2012)<sup>68</sup>. Using data from the Medical Expenditure Survey, this study found mothers of children with ASD earned 35% and 56% less than those with children with a different health condition or without a health condition, respectively<sup>68</sup>. Fathers also earned 21% and 28% less than those with children with and without a health condition, respectively<sup>68</sup>. Negative labor market outcomes have been attributed to problems with child-care and the large burden of raising a child with ASD, including coordinating their complex care<sup>68</sup>. It is likely this financial impact will be sustained as the youth ages since youth with ASD are almost 3 times more likely to remain in their parent's residence throughout the lifespan compared to typically-developing children<sup>69</sup>.

## 2.6 Psychiatric Treatments, Service Use and Barriers to Care

Only two treatments have been approved by the Food and Drug Administration to treat comorbid psychiatric symptoms in ASD<sup>70</sup>. This includes use of risperidone and aripiprazole to treat tantrums or aggression among early school-aged children with ASD. Serious side-effects are known to accompany these medications, however. This includes, but is not limited to, weight gain, gynecomastia, drowsiness, and involuntary movements such as tardive dyskinesia<sup>70</sup>. Combining parent training interventions with these medications have also shown to modestly increase treatment effects<sup>70</sup>. The Cochrane group has reviewed the literature on numerous treatments for co-occurring psychiatric symptoms among this population<sup>71</sup>. Outside of risperidone and aripiprazole, the Cochrane group has not supported the efficacy or effectiveness of any other pharmacologic or non-pharmacologic treatment of psychiatric symptoms in ASD<sup>71</sup>.

Despite a dearth of federally approved interventions for psychiatric symptoms in ASD, there are two well-established mental health treatments available to parents and clinicians. The most heavily researched and well supported non-pharmacologic interventions include Cognitive Behavioral Treatments (CBT) for internalizing symptoms and Applied Behavioral Analysis (ABA) for externalizing behaviors<sup>70</sup>. CBT focuses on restructuring the cognitive mechanisms that underlie destructive pattern of thinking and ultimately lead to mental health disorders such as anxiety and depression. ABA seeks to understand and alter the function of challenging behavior through techniques such as reinforcement and discrete trail training. While CBT has been adapted for use in ASD, the strategies require language skills and normal (IQ>70) intellectual functioning<sup>70</sup>. ABA, on the other hand, has been designed for all individuals with ASD<sup>70</sup>.

Interventions that focus on improving the mental health systems serving youth with ASD have received much less attention, however. These interventions include respite care, day hospitalization, service coordination, positive behavioral supports, wrap-around services, and crisis prevention-intervention programs. To date, there is little to no research on these interventions in ASD. The goal of Aim 2 is to help fill this gap by examining the START program. START is a tertiary care crisis prevention and intervention program that seeks to enhance local capacity, promote the development of least-restrictive life-enhancing services and supports, and provide education as well as training to providers and caregivers. START supports individuals with a developmental disability and challenging behavior through a host of services ranging from service coordination, clinical/medical consultation, 24/7 crisis response services to outreach. More information about START and outcomes associated with this

program can be found in Chapter 5.

Understanding what psychiatric services a child with ASD receives is complex since services can be paid for and delivered through the educational system as well as public and private insurance. Narendorf and colleagues (2002) is one of the few to report on mental health service use in the educational setting<sup>72</sup>. Using the 2002 Medical Expenditure Panel Survey (MEPS), they found that, among adolescents 13-16 with ASD, 49% of parents reported their child received “any psychological or mental health services or counseling” in the last 12 months within the school setting<sup>72</sup>. Interestingly, Kang et al. (2015) examined the role of Medicaid in paying for mental health services in the school setting, and reported a similar figure in the state of Pennsylvania<sup>73</sup>. That is, 52% of children who received Medicaid received in-school behavioral services paid for by their public insurance<sup>73</sup>.

Much more research has examined the role of public and private insurance in delivering mental healthcare to children with ASD. The 3 studies that have employed private insurance databases report a range of 40%-68% of the sample received outpatient services, while between 1-3% received an inpatient psychiatric hospitalization, over the course of a year<sup>74-76</sup>. For youth covered by Medicaid, a large range, from 20%-98%, has been reported for use of outpatient mental health services<sup>77-79</sup>. This variation is likely do to differential inclusion of behavioral services, such as applied behavior analysis, in the study with the highest estimate. On the other hand, rates of inpatient hospitalization (1-2%) in Medicaid are similar to those seen in the privately insured population<sup>76,78,79</sup>. Although the data are now over a decade old, a recent comparison of expenditures between the private and public insurers found the public payer system spends ten

times more on behavioral and mental healthcare per child with ASD compared to the private payer system<sup>76</sup>. This difference was entirely made up of differences in outpatient mental healthcare costs.

Two national and one local survey-based study have also examined receipt of mental health services among children with ASD. Both of the studies using national surveys reported roughly half of children with ASD in the US ever receiving any mental healthcare<sup>21,80</sup>. Moreover, only one survey-based study has examined rates of psychiatric hospitalization among youth with ASD in the US. Mandell (2007) reported an 11% lifetime prevalence of psychiatric hospitalization among youth 6-17 years of age, based on a local survey of 760 parents in the state of Pennsylvania<sup>81</sup>. Reconciling the differences between surveys and claims data are difficult since they are drastically different in terms of sampling and measurement of both the study population and outcome.

Several studies have also examined use of the emergency department for mental health purposes among those with ASD. This topic has recently received increased attention since the rate of psychiatric ED visits among youth in the US has been steadily rising over the last two decades<sup>82,83</sup>. Use of the ED for psychiatric care is disconcerting since the setting may be traumatic for the child and family due to long wait times, the ED environment is known to be chaotic, and ED staff are often untrained in proper management of this population<sup>83</sup>. Using the 2008 National Emergency Department Sample (NEDS), Kalb et al. (2012) reported that 13% of ED visits among children with ASD were psychiatrically-related, compared to 2% of all pediatric ED visits (aOR= 9.13, 95% 8.61-9.70)<sup>84</sup>. These findings were replicated by Iannuzzi (2014) using

the 2010 NEDS dataset<sup>85</sup>. These studies possess several limitations, however. The first challenge is the NEDS data exists at the visit, not patient, level. As a result, it is unknown if a single child contributed to one or multiple visits. The NEDS also requires ED physicians, who have limited training in neurodevelopmental disorders, to assess whether a child has ASD. The NEDS is also cross-sectional, which precludes assessing trends over time. Lastly, all of these studies have employed typically developing children as the reference group. Use of a special healthcare needs comparison group is important because it helps mitigate the concern that an ED visit may be misclassified as psychiatrically-related given the child's history of psychiatric symptoms rather than the presenting problem. Reported in Chapter 3, the goal of Aim 1 is to overcome these limitations by conducting a prospective cohort study, using private insurance claims, of psychiatric ED use among youth with ASD compared to youth with ADHD and no ASD, and youth without ASD or ADHD.

Use of the ED for psychiatric purposes has been historically linked to de-institutionalization and poor connections to outpatient mental healthcare<sup>83</sup>. While it is presently not known if psychiatric ED use is a byproduct of an unfit mental health system serving children with ASD, although Study 1 will shed some light on the topic, these families do indeed report problems with accessing mental healthcare for their child. The most intensive study assessing the quality of mental healthcare among this population comes from Brookman-Frazee (2012)<sup>17</sup>. The authors conducted 21 semi-structured qualitative interviews among parents of children with ASD receiving psychiatric services for their child in a community mental health clinic. From these interviews the authors stated that navigating the mental health system was difficult and stressful for parents and there was a dearth of trained clinicians in ASD to serve these children<sup>17</sup>.

The greatest difficulty with the study by Brookman-Frazee (2012) is generalizability, given the small convenience sample. However, national data appears to support these authors' conclusions. Using data from the National Survey of Children's Health, Chiri & Warfield (2012) reported access to mental health care was the service with the highest unmet need, at 15%, among youth with ASD<sup>18</sup>. More specifically, parents of children with ASD were three times more likely to endorse that mental health provider(s) 'did not know how to treat' their child compared to children with other special healthcare needs. A different study<sup>80</sup> using the same dataset as Chiri & Warfield (2012) extended these finding, such that problems with access to care was actually higher among children with ASD who have a co-morbid psychiatric disorder compared to those without a concurrent psychiatric diagnosis.

Difficulty with access to high quality care is clearly not specific to psychiatric care among this population. Three studies using national survey data all converge on the same finding: parents of children with ASD report greater problems with access to and poorer quality of healthcare compared to other children with special healthcare needs<sup>16,19,20</sup>. Specific problems include: 1) poor communication between providers, 2) problems with insurance coverage, 3) delays in care, and 4) lack of partnership with parents in care. Parental report of sub-optimal care by the healthcare system is also substantiated by the providers themselves. For instance, a national survey of physicians found the providers felt they lacked adequate training and clinical skills to treat and diagnose ASD<sup>87</sup>.



## 2.7 Mental Health Crisis

The earliest writings on crisis theory date back to the very beginning of the 20<sup>th</sup> century, where Thomas (1909) defined a crisis as “a threat, a challenge, a strain on the attention, a call to new action, which may have the germ of a new organization”<sup>88</sup>. In the 1940s and 50s, Eric Lindemann expanded this work with a focus of crises being linked to mental health, particularly in reaction to grief and loss<sup>89</sup>. In the 1960s, Caplan went on to define the 4 stages of crisis and in the 1980s Hobbe’s work on the “crisis curve” extended Caplan’s prior research suggesting that at each stage of crisis an individual draws on their positive coping strategies<sup>90,91</sup>. Today, perhaps the most popular definition of crisis comes from Roberts (2000), who defines crisis as “an acute disruption of psychological homeostasis in which one’s usual coping mechanisms fail and there exists evidence of distress and functional impairment”<sup>92</sup>.

Much more has been written about crisis then there have been attempts at developing a useful or psychometrically sound measure of such. After reviewing the literature, I have been able to identify five published/peer-reviewed crisis measures: 1) The Psychiatric Emergency Service Interview<sup>93</sup>, 2) The Crisis Triage Rating Scale<sup>94</sup>, 3) The Triage Assessment Form<sup>95</sup>, 4) The Suicide Assessment Checklist<sup>96</sup>, and 5) The Crisis Risk and Adaptive Functioning Tool (CRAFT)<sup>97</sup>. Interestingly, they all share the same significant drawbacks that make them inapplicable to youth with ASD. First, none of these measures were designed for children, much less those with a developmental disability. Second, all of these measures require clinician administration, which limit their accessibility for research. Third, most of these measures lack strong psychometric and theoretical properties.

Very recently Drs. Jonathan Weiss and Yona Lunsky published three papers proposing measurement and theory behind crisis in autism<sup>98-100</sup>. The authors began their work by defining crisis using ground-up, qualitative interviews among 157 Canadian parents<sup>99</sup>. Results from this work suggested the following themes regarding how these parents view crisis: 1) it was related to the child's behavioral problems and difficulty with service providers, 2) crises were frequent and pervasive with deleterious effects on the family, 3) families often sought emergency service use for crises, such as the hospital and police, and 4) parents desired increased social and professional support to manage the crisis-related events.

The authors used these results to develop the Brief Family Distress Scale (BFDS)<sup>100</sup>, which consists of a single question and not a collection of items indicative of the term scale. The item asks parents to rate where they and their family members “are” at the current moment. On a scale of 1-10, responses range from “Everything is fine, my family and I are not in crisis at the moment” to “We are currently in crisis, and it could not get any worse”. The measure was positively associated with a host of factors, such as negative life events, financial problems, poor quality of life, and the child's problem behavior.

There are several important limitations to the BFDS. First, no psychometric analysis occurred on the scale, given it was a single item. Thus, reliability and validity could not be established given a latent attribute requires multiple indicators/observed variables. Second, the clinical utility of the item is questionable since a host of disparate constructs (e.g., recent loss of a loved one) correlated with the BFDS. Meaning, what does one exactly do with this information and how does it inform treatment? Third, this item relies on the assumption that all families equally

understand what a crisis entails. This high level of subjectivity could result in serious measurement bias.

Taken together, much has been written about mental health crisis and crisis theory over the last century. However, this work has not translated well into a clinically useful crisis assessment tool. The goal of Aim 2 is to overcome the major impediments seen in these instruments for the purpose of identifying those families in greatest need for intervention.

## 2.8 Summary

The current review of the literature makes several important issues clear. First, a preponderance of children with ASD suffers from a comorbid psychiatric disorder(s)<sup>6,8,52</sup>. Second, parents of these children are incredibly stressed and distressed<sup>59,60</sup>. Third, there is a dearth of evidence-based mental health interventions for these children<sup>70,71</sup>. Fourth, accessing high quality health care, particularly mental health care, for their child is an enduring difficulty for parents of children with ASD<sup>17,18,20,21</sup>. Fifth and finally, increased psychiatric symptoms in the child make parenting and accessing care more difficult<sup>80</sup>. The totality of these problems places these children at risk for a mental health crisis.

The current proposal takes a tripartite approach to assessing mental health crisis among youth with ASD. Since no appropriate measure of crisis currently exists for this group, the goal of Study 1 is to substantiate the theory that this population is indeed at increased risk for mental health crisis by examining differences in one measure of crisis--the rate of emergency psychiatric service use--among youth with ASD compared to youth with ADHD. Study 2 addresses the

present lack of crisis measurement for children with ASD by examining the psychometric characteristics of the MCAS, a mental health crisis measure designed by this author and his team. The third and final study addresses the actual treatment of mental health crisis, given the present dearth of crisis-focused interventions, by investigating the START crisis prevention and intervention program. The overarching goal of the current proposal is to address mental health crisis from three unique perspectives (service use, measurement, and intervention) with the goal of reducing the occurrence and impact of mental health crisis among this vulnerable population.

**CHAPTER 3: CHARACTERISTICS OF PSYCHIATRIC EMERGENCY  
DEPARTMENT USE AMONG PRIVATELY INSURED ADOLESCENTS WITH  
AUTISM SPECTRUM DISORDER (STUDY 1)**

### 3.1 Background

The American Academy of Pediatrics (AAP) and the American College of Emergency Physicians (ACEP) have released joint statements addressing the clinical challenges presented by pediatric psychiatric emergencies in the emergency management system<sup>83,101</sup>. These reports were motivated by the sustained increase in psychiatric-related pediatric emergency department (ED) visits, despite the declining number of EDs, nationwide<sup>83</sup>. Between 2001 and 2011, the annual rate of pediatric psychiatric ED visits nearly doubled from 13.6 to 25.3 visits per 1,000 adolescents, whereas the total number of EDs decreased by 5% during this same period<sup>102,103</sup>.

The increasing prevalence of ASD in the US, which is now estimated at 1 in 68 children, has raised concerns about the growing presence of this population in the emergency management system<sup>104</sup>. ED visits have become a topic of particular interest among this group since the sensory, social, and communicative deficits inherent to ASD make this environment particularly difficult to tolerate. If a parent uses the ED for psychiatric management, this setting becomes even less suitable since there are few resources available to manage an acute psychiatric event involving a child with ASD<sup>105</sup>. As such, ED clinicians may be inclined to prescribe chemical and physical restraints to manage these children<sup>106</sup> and finding an inpatient unit to accept this population upon discharge will be difficult since most child psychiatry inpatient units will refuse to admit youth with a developmental disability<sup>107</sup>. Ultimately, parents may experience stress, frustration, and disillusionment with the medical system as they wait for long periods in the ED and are sent home to manage their child's psychiatric symptoms with little to no additional mental health resources<sup>108</sup>.

Despite the aforementioned concerns, a growing body of literature suggests that parents of youth with ASD are more likely to use the ED for psychiatric purposes compared to parents of youth without ASD. Using the 2008 National Emergency Department Sample (NEDS), Kalb et al. (2010) found that 13% of ED visits among children with ASD were for psychiatric reasons, compared to 2% of all non-ASD pediatric ED visits<sup>109</sup>. Iannuzzi (2014) and Vohra and colleagues (2016) replicated these findings using an updated version of the NEDS<sup>85,110</sup>. These studies possess several limitations, however. The first challenge is the NEDS data exists at the visit, not patient, level. As a result, it is unknown if a single child contributed to one or multiple visits. The NEDS also requires ED physicians, who have limited training in neurodevelopmental disorders, to assess whether a child has ASD. Lastly, the NEDS is cross-sectional, which precludes assessing trends over time.

Recently, Liu et al. (2017) employed the MarketScan commercial claims databases in order to overcome many of the challenges inherent to the NEDS. Results of this study showed a near doubling, from 12% in 2005 to 22% in 2013, in the proportion of ED patients with ASD who received behavioral health services during their visit. The major limitation of this study is behavioral health visits included the diagnosis of ASD (ICD 299.XX). As a result, any visit in which the ED physician included ASD as a billing code (the MarketScan dataset allows for up to 15 diagnostic codes) was classified as behavioral health-related even if the visit was for a medical reason. While the current study utilizes the same dataset as Liu et al. (2017), we employed a different set of aims and methods.

The goal of this study was to conduct an in-depth examination of psychiatric ED visits among adolescents with ASD as well as the interplay between psychiatric inpatient (including hospitalization and ED use) and outpatient care. More specifically, the first aim of this study examined differences in the rate of psychiatric-related ED visits among adolescents with ASD, adolescents with ADHD, and adolescents without either ASD or ADHD between 2010 and 2013 using an administrative claims database from a national sample of privately insured individuals. The second objective was to assess group differences in the reason for the psychiatric ED visit. The third and final objective was to examine differences across diagnostic groups in access to outpatient care 30 days before and after the ED visit, the probability of readmission to the ED within 30 or 90 days after the psychiatric ED visit, and the proportion of ED visits that resulted in psychiatric hospitalization.

### **3.2 Methods**

#### **3.2.1 Sample**

The primary dataset used for this study is the Thomson Reuters Truven Marketscan database<sup>111</sup>. Totalling approximately 17 million enrollees per year (and growing over time), the Marketscan database includes claims covered under a variety of healthcare plans, including fee-for-service, and fully as well as partially capitated health plans, from more than 200 large private insurance firms across the United States<sup>111</sup>. Due to confidentiality reasons, information about the employer-sponsored health insurance firms that participate in the Marketscan database is unavailable.

The Marketscan database contains all inpatient and outpatient claims for both mental health



and general healthcare services for enrollees and their dependents between 2008 and 2012. Variables also contained in Marketscan include procedure codes, service dates, and diagnoses based on *International Classification of Disease Version 9* Codes<sup>112</sup>. Unique, anonymous individual identifiers allow researchers to track individuals over year and across medical settings. Basic enrollment information (i.e., age, sex, region) for all insured individuals is available. Given the de-identified nature of the data, the local Institutional Review Board deemed this study exempt from human subjects research review.

### 3.2.2 Inclusion Criteria

To be included in the present study, adolescents must be between 12 and 17 years of age; representing the developmental period when psychiatric ED use peaks<sup>84,85,113</sup>. Since the unit of analysis was child-calendar year, the child must have been enrolled in their caregiver's private insurance plan for at least 12 months to eliminate group differences in the days enrolled within each year. The proportion of children who were continuously enrolled within each year (76%) was similar over time (2008-2012) and across diagnostic groups.

Adolescents with ASD and adolescents with ADHD were identified as those with at least two reimbursed inpatient or outpatient claims that included the diagnostic code of ICD-9 Code 299.XX or 314.XX, respectively<sup>114</sup>. In an attempt to avoid misclassification, individuals in the ADHD group were removed if they had any history of an ASD-related claim [n= 3,694 children were excluded who had 2 ADHD and 1 ASD-related claim(s)]. The ADHD group served as a comparison population because, similar to ASD, it is a neurodevelopmental disorder with extensive psychiatric comorbidity and previous studies have uniformly employed non-special

healthcare needs comparison groups<sup>44,85,110</sup>. Use of a special healthcare needs comparison group also helps mitigate the concern that an ED visit may be misclassified as psychiatrically-related given the child's history of psychiatric symptoms rather than the presenting problem.

The second comparison group was comprised of a 20% random sample of children enrolled in MarketScan between 2010-2013 who were continuously enrolled for at least 12 months in a single year and did not have any ASD- or ADHD-related claims. This group was included as a reference group in order to provide information about baseline psychiatric ED use among non-affected adolescents in this privately-insured sample.

### 3.3.3 Visit Coding

Consistent with previous research methods, psychiatric ED visits and psychiatric inpatient hospitalizations were identified when the primary or first diagnosis billed indicated a psychiatric disorder (ICD-9 290-319.XX)<sup>115-117</sup>. This diagnosis ostensibly represents the primary reason for or the cause of the visit<sup>118</sup>. If ASD or ADHD was listed first, these visits/hospitalizations were considered psychiatric given the nature of these diagnoses. Moreover, psychiatric ED visits that resulted in hospitalization were identified by those visits that were associated with a psychiatric inpatient hospitalization either the day of or the day following the ED visit. Outpatient mental health visits were identified when a reimbursed claim was submitted by a mental health professional or a mental health-related procedure was billed during the visit.

### 3.3.4 Statistical Analysis

Chi-Square and ANOVA analyses were used to examine differences in demographic variables across the three groups: adolescents with ASD, ADHD and neither of these diagnoses. If the overall test statistic indicated a difference across all 3 groups ( $p < .05$ ), linear and logistic regression models were used to perform pair-wise contrasts. For the primary study objective, to examine group differences in the rate (or log count) of psychiatric ED visits at the child-calendar year, a negative binomial regression model was employed. This model was selected among other count-based regression models (e.g., poisson) based on Bayesian and Akaike Information Criterion values. Moreover, logistic regression models were used to assess differences between groups in: a) the reason for visit, b) a repeat psychiatric ED visit within 30 or 90 days, and c) probability of a psychiatric ED visit resulting in an inpatient psychiatric admission. To address differences in the rate of outpatient mental healthcare 30 days before and 30 days after the psychiatric ED visit, a negative binomial regression model was used. All regression models adjusted for the 5 demographic variables shown in Table 1.

For the analyses examining access to outpatient care before and after the psychiatric ED visit, repeat psychiatric ED visits, and the probability of a psychiatric ED visit resulting in an inpatient psychiatric admission, we only examined the adolescents' first psychiatric ED visit that did not result in a hospitalization. This approach was taken to avoid survivor treatment selection bias and ensure the child remained in the community where the receipt of outpatient care or a repeat ED visit could be observed<sup>119</sup>. Robust standard errors were used to account for the clustering of the data, alpha was set at .05 for all variables, and STATA 12.0 (College Station, Tx) was used for data management and to conduct the analyses.

### 3.4 Results

#### 3.4.1 Demographics

Table 1 displays the demographic characteristics across the three groups. Adolescents with ASD ( $\beta = -0.17$ , 95% CI: -0.18, -0.12) and adolescents with ADHD ( $\beta = -0.13$ , 95% CI: -0.13, -0.12) were enrolled in their private insurance plan for a slightly fewer years, on average, than adolescents without either diagnosis; whereas, little difference was observed between adolescents with ASD and adolescents with ADHD ( $\beta = -0.05$ , 95% CI: -0.06, -0.04). Adolescents with ASD ( $\beta = -0.66$ , 95% CI: -0.67, -0.65) and adolescents with ADHD ( $\beta = -.49$ , 95% CI: -0.50, -0.48) were also slightly younger than adolescents without either diagnosis; again, little difference in age emerged between adolescents with ASD and adolescents with ADHD ( $\beta = -.17$ , 95% CI: -0.18, -0.15). On the other hand, adolescents with ASD were disproportionately male compared to adolescents without either diagnosis (OR = 4.1, 95% CI: 4.0, 4.2) or to adolescents with ADHD (OR = 1.9, 95% CI: 1.8, 2.0). Adolescents with ADHD were also more likely to be male compared to adolescents without either diagnosis (OR = 2.1, 95% CI: 2.1, 2.2). Multiple regional differences also emerged across the groups (see Table 1 for details). All group differences reported above were  $p < .01$  and each of the variables were included as covariates in the multivariate models discussed below.

#### 3.4.2 Psychiatric ED visits

Table 2 displays the average number of visits across groups and over time. Overall, adolescents with ASD had an increased rate of psychiatric ED visits (M = 5.7 visits per 100 adolescents per year) compared the other two groups (neither diagnosis: IRR = 9.6, 95% CI: 9.1, 10.0; ADHD: IRR = 2.0, 95% CI: 1.9, 2.1, both  $p < .001$ ). The ADHD group also had more visits (M = 3.1 visits

per 100 adolescents per year) compared to adolescents without either diagnosis (IRR = 4.9, 95% CI = 4.8, 5.1), whose rate of visits was very low (M = 0.6 visits per 100 adolescents per year). Over time, there was no change in psychiatric ED visits among adolescents with ASD (IRR = .96, 95% CI = .92, 1.0,  $p=.07$  for linear time trend). For those with ADHD, there was a slight decrease in visits over time (IRR = .93, 95% CI = .91, .95,  $p<.001$ ), while there was small increase for those without either diagnosis (IRR = 1.05, 95% CI = 1.04, 1.06,  $p<.001$ ).

### 3.4.3 Reason for Visit

In the multivariate models, which conditioned on the occurrence of a visit, adolescents with ASD were more likely to visit the ED due to a psychotic disorder (OR = 1.6, 95% CI: 1.4, 1.9), conduct/oppositional-defiance disorder (OR = 3.0, 95% CI: 2.7, 3.3), and all other psychiatric disorders (OR = 1.95, 95% CI: 1.8, 2.1) compared to adolescents without either diagnosis. On the other hand, they were less likely to visit the ED due to a substance use disorder (OR = 0.1, 95% CI: 0.2, 0.1; all  $p<0.001$ ) and equally likely to visit the ED for a mood disorder (OR = 1.0, 95% CI: 0.9, 1.0,  $p=0.5$ ) compared to adolescents without either diagnosis. In the same vein, adolescents with ASD were more likely to visit the ED for a psychotic disorder (OR = 2.0, 95% CI: 1.7, 2.4), conduct/oppositional-defiance disorder (OR = 1.5, 95% CI: 1.4, 1.6), and all other psychiatric disorders (OR = 2.1, 95% CI: 2.0, 2.3) compared to those with ADHD; although, they were less and less likely to visit the ED for a substance-use (OR = 0.1, 95% CI: 0.1, 0.2) or mood disorder (OR = 0.8, 95% CI: 0.8, 0.9) compared to those with ADHD. Finally, youth with ADHD were more likely to visit the ED for a mood (OR = 1.3, 95% CI: 1.2, 1.3) or conduct/oppositional-defiance disorder (OR = 2.0, 95% CI: 1.9, 2.1) and less likely for a psychotic (OR = 0.8, 95% CI: 0.7, 0.9), SUD (OR = 0.6, 95% CI: 0.6, 0.7), or any other

psychiatric disorder (OR = 0.9, 95% CI: 0.8, 0.9; all  $p < .001$ ) compared to adolescents without either diagnosis.

#### 3.4.4 Inpatient Psychiatric Hospitalization

A larger proportion of visits among adolescents with ASD (15%) and adolescents with ADHD (14%) resulted in a psychiatric hospitalization compared to adolescents without either diagnosis (7%). These results were maintained in the adjusted analyses, such that visits among both adolescents with ASD (OR = 2.6, 95% CI: 2.4, 2.9) and those with ADHD (OR = 2.1, 95% CI: 2.0, 2.2) were more likely to result in a psychiatric hospitalization compared to visits among adolescents without either diagnosis. Adolescents with ASD were also slightly more likely (OR = 1.2, 95% CI: 1.1, 1.3) to have a psychiatric ED visit result in a psychiatric hospitalization compared to adolescents with ADHD (all  $p < .001$ ).

#### 3.4.5 ED recidivism

The 38,041 1<sup>st</sup> ED visits (55% of total visits) that did not result in hospitalization were assessed for ED recidivism within 30 and 90 days. In the multivariate analysis, adolescents with ASD were more likely to have a repeat visit within 30 days (OR = 1.6, 95% CI: 1.4, 1.8) and 90 days (OR = 2.2, 95% CI: 1.9, 2.4) than adolescents without either diagnosis or adolescents with ADHD (30 days, OR = 1.3, 95% CI: 1.1, 1.5; 90 days, OR = 1.5, 95% CI: 1.3, 1.5). Similarly, adolescents with ADHD were more likely to have a repeat visit within 30 days (OR = 1.2, 95% CI: 1.1, 1.4) and 90 days (OR = OR = 1.5, 95% CI: 1.4, 1.6) than adolescents without either diagnosis (all  $p < .001$ ).

### 3.4.6 Outpatient Mental Health Treatment

Adolescents with ASD had more outpatient mental health visits 30 days prior to their first psychiatric ED visit than adolescents without either diagnosis (IRR = 2.1, 95% CI: 1.9, 2.2) and adolescents with ADHD (IRR = 1.2, 95% CI: 1.1, 1.3). A similar trend was observed for those with ADHD compared to those without ASD or ADHD (IRR = 1.8, 95% CI: 1.7, 1.8; all  $p < .001$ ). Thirty days after the first psychiatric ED visit, adolescents with ASD had more outpatient visits than did adolescents without either diagnosis (IRR = 3.2, 95% CI: 3.0, 3.6) and slightly more visits than adolescents with ADHD (IRR = 1.4, 95% CI: 1.3, 1.5). A similar relationship was observed for those with ADHD compared to those without ASD or ADHD (IRR = 2.3, 95% CI: 2.2, 2.5).

## 3.5 Discussion

This study provides an in-depth examination of psychiatric ED visits involving adolescents with ASD. Compared to the two other control groups, adolescents with ASD were more likely to use the ED for psychiatric reasons as well as revisit the ED 30 or 90 days after their first psychiatric ED visit. Despite this finding, two separate surveys of ED providers both concluded that ED staff feel under-trained and under-resourced when managing adolescents with ASD in the ED<sup>120,121</sup>. Although efforts are underway to improve the training of ED staff in ASD<sup>120</sup>, further research is needed to understand if these interventions can improve the care of children with ASD in the ED who are experiencing a mental health event.

In contrast to Liu et al. (2017), we did not find an increase in psychiatric ED visits among youth with ASD over time. This divergent finding may be explained by the inclusion of both young adults (18 to 21 years) and adolescents (12 to 17 years) in Liu et al. (2017), whereas our study

solely focused on adolescents. Perhaps most importantly, Liu et al. (2017) classified any visit with ASD on the billing code as a behavioral health visit, even if a comorbid psychiatric disorder was not coded. Our study, on the other hand, examined visits involving youth with ASD if the principal or first listed diagnosis was a psychiatric diagnosis. Results from this study are likely more conservative given our criteria for identifying psychiatric ED visits was more stringent.

Mood disorders were the most common reason for ED visits among all diagnostic groups. This finding is consistent with the literature demonstrating adolescence is a critical time for the development of depression and anxiety, which are linked to deleterious outcomes such as self-injury and suicide <sup>122</sup>. Two other diagnoses that were elevated among adolescents with ASD compared to adolescents with ADHD and adolescents without either diagnosis were oppositional/conduct disorder and psychotic disorders. Previous research has implicated both of these disorders as common reasons for ED visits among adolescents with ASD <sup>109,110</sup>, suggesting these diagnoses are important targets for outpatient intervention.

Our results did not support the notion that adolescents with ASD had increased psychiatric ED visits due to a lack of outpatient mental healthcare before or after their visit. The same finding held true for adolescents with ADHD. Other research has also found that those who seek mental healthcare in the ED often have a connection to outpatient providers <sup>116,123,124</sup>. Explanations for this counterintuitive finding include the possibility that the mental health provider referred the child to the ED for crisis management <sup>105,108</sup>, families who use the ED for mental healthcare require a greater intensity of services than those afforded to them during routine outpatient



mental health visits, or families find the ED a convenient and responsive source of support for their child's immediate mental healthcare needs <sup>123</sup>.

Taken together, we believe more research is needed to better understand how to prevent psychiatric ED use. The difficulty of this task cannot be understated since psychiatric ED visits are a multifarious phenomenon that have been linked to structural barriers such as socioeconomic status and ethnic/racial trends <sup>125</sup>, geographic location and rurality<sup>126</sup>, residence <sup>127</sup>, and lack of insurance <sup>126</sup>. On the other hand, there appears to be room for intervention, such as educating parents about using the ED to manage non-urgent psychiatric events <sup>128</sup>, increasing access to respite care <sup>129</sup> and structured day time activities <sup>127</sup>, and reducing parental and family stress <sup>127</sup>. Further research into programs such as the START (Systematic, Therapeutic, Assessment, Resources, Treatment) <sup>130</sup> and ATC (Assertive Community Treatment) <sup>131</sup> programs is also warranted since these coordinated, multidisciplinary approaches may be more fruitful in addressing the numerous risk factors for psychiatric ED use than routine outpatient care.

Despite the shortage of inpatient psychiatric units designed for those with ASD in the US <sup>107</sup>, the proportion of psychiatric ED visits that resulted in a psychiatric hospitalization was greatest among this group (15%). As a result, adolescents with ASD may be placed on general pediatric psychiatric units where the resources and training required to provide optimal care for this population may not be available <sup>107</sup>. If future research replicates this finding, it will be critical for general psychiatry inpatients units to develop models of care to accommodate youth with ASD.

Several limitations about this study should be mentioned. Inherent to the nature of claims-based research, all diagnoses are based solely on clinician billing practices. This raises concerns about diagnostic validity of the groups, due to the lack of gold standard measures, and visit misclassification, due to inconsistent coding patterns. Second, comparability between groups may be compromised due to the lack of information about as well as the inability to control for potential confounders such as family health and wellbeing, socioeconomic status, and services received outside the insurance plan. Third, these data represent a selected private insurance sample and likely do not generalize to those with Medicaid, the uninsured, or children in the US as a whole. These limitations are offset by several novel questions addressed by this study, the prospective design, and the use of objective, claims-based data rather than reliance on retrospective recall.

In sum, this study indicates that adolescents with ASD are more likely to visit the ED for psychiatric reasons compared to adolescents with ADHD and adolescents without either diagnosis. Increased psychiatric ED use was not simply a product of decreased access to outpatient care, suggesting that other factors are contributing to these visits. Clinicians should be prepared to address the mental health needs of adolescents with ASD in emergency settings, while researchers are tasked with developing strategies to reduce these visits and subsequent inpatient hospitalizations.

Chapter 3: Table 1, Demographic Differences between Diagnostic Groups

	ASD	ADHD	Neither diagnosis
N	46,343	408,066	2,330,332
Age, M (SD)	13.9 (1.6)* <sup>‡</sup>	14.1 (1.6) <sup>€</sup>	14.6 (1.6)
Gender (% male)	80* <sup>‡</sup>	68 <sup>€</sup>	49
Years Enrolled, M (SD)	2.3 (1.0)* <sup>‡</sup>	2.4 (1.0) <sup>€</sup>	2.5 (1.0)
Region (%)			
Northeast	25* <sup>‡</sup>	16 <sup>€</sup>	18
North Central	26* <sup>‡</sup>	27 <sup>€</sup>	24
South	26* <sup>‡</sup>	39 <sup>€</sup>	34
West	19* <sup>‡</sup>	14 <sup>€</sup>	21

\* =  $p < .05$  contrast between ASD vs. ADHD

<sup>‡</sup> =  $p < .05$  contrast between ASD vs. No ASD and No ADHD

<sup>€</sup> =  $p < .05$  contrast between ADHD vs. No ASD and No ADHD

Chapter 3: Table 2, Characteristics of Psychiatric ED Visits

	ASD	ADHD	Neither diagnosis
Total Psychiatric ED Visits (M visits per 100 youth)			
2010	6.6	3.5	0.6
2011	5.3	3.0	0.7
2012	5.5	3.1	0.7
2013	5.7	2.9	0.8
Overall	5.7* <sup>†</sup>	3.1 <sup>€</sup>	0.7
Psychiatric Diagnosis/Reason for ED Visit (%)			
Mood Disorder	45 <sup>†</sup>	54 <sup>€</sup>	52
Oppositional-Defiant/Conduct Disorder	17* <sup>†</sup>	10 <sup>€</sup>	4
Psychosis-related Disorders	4* <sup>†</sup>	2 <sup>€</sup>	2
Substance Use Disorders	2* <sup>†</sup>	16 <sup>€</sup>	22
All other psychiatric diagnoses	32* <sup>†</sup>	18 <sup>€</sup>	20
Psychiatric ED visits that resulted in a hospitalization <sup>‡</sup> (%)	15* <sup>†</sup>	14 <sup>€</sup>	7
Repeat Psychiatric ED Visit <sup>‡</sup> (% of ED visits)			
Within 30 days	9* <sup>†</sup>	7 <sup>€</sup>	6
Within 90 days	16* <sup>†</sup>	11 <sup>€</sup>	8

Outpatient Care			
30 days <u>prior</u> to ED visit <sup>£</sup> (Mean Visits)	1.9* <sup>‡</sup>	1.7 <sup>€</sup>	1.0
30 days <u>after</u> ED visit <sup>£</sup> (% of ED visits)	1.1* <sup>‡</sup>	0.9 <sup>€</sup>	0.4
<p>* = p&lt;.05 contrast between ASD vs. ADHD</p> <p>‡ = p&lt;.05 contrast between ASD vs. No ASD and no ADHD</p> <p>€ = p&lt;.05 contrast between ADHD vs. No ASD and no ADHD</p> <p>£ = only 1<sup>st</sup> visits that did not result in a hospitalization were assessed</p>			

**CHAPTER 4: PSYCHOMETRIC CHARACTERISTICS OF THE MENTAL HEALTH  
CRISIS ASSESSMENT SCALE IN YOUTH WITH AUTISM SPECTRUM DISORDER  
(STUDY 2)**

## 4.1 Introduction

Urgent behavioral health problems are frequently exhibited by youth with autism spectrum disorder (ASD). Roughly half of these youth exhibit aggression <sup>9,10</sup>, a third experience wandering/elopement <sup>11</sup>, and about thirty percent engage in self-injurious behavior <sup>12</sup>. These behaviors can result in full blown crisis episodes that pose a danger to self and others. The pressing need to manage these psychiatric symptoms has resulted in high rates of polypharmacy, emergency room visits, and inpatient psychiatric hospitalization among this population <sup>81,84,132</sup>.

The core features of ASD (i.e., social deficits, communication delays, and the presence of restricted and repetitive behaviors; <sup>36</sup> may themselves be an intrinsic diathesis for crisis. The complex interactions between ASD symptoms, cognitive features of ASD (e.g., intellectual disability, Newschaffer et al., 2007), and environmental stressors (e.g., bullying; Zablotzky, Bradshaw, Anderson, & Law, 2014) may place this population at particularly high risk for crisis. Developing a mental health crisis scale for youth with ASD is, therefore, critical to prevent a crisis or intervene early in those who are at high risk for these events. Failure to recognize and treat these problems can result in loss of education, employment, housing, and severe caregiver burnout <sup>6,133</sup>.”

The concept of a mental health-related crisis has existed for at least a century <sup>92</sup>. Sociologist Albert Roberts (2000) defined crisis as “an acute disruption of psychological homeostasis in which one’s usual coping mechanisms fail and there exists evidence of distress and functional impairment” <sup>92</sup>. The American Psychiatric Association’s Task Force on Psychiatric Emergencies (2002) defined a psychiatric emergency as “an acute disturbance of thought, mood, behavior or

social relationship that requires immediate intervention and the resources available to understand and deal with the situation are not available at the time and place of the occurrence”<sup>22</sup>. These definitions emphasize two core elements of crisis: 1) the presence of acute psychiatric symptoms and 2) a lack of immediate resources available to manage the event.

Although the concept of crisis has been well-established, only a handful of measures that capture this construct exist. Currently available instruments include the Psychiatric Emergency Service Interview<sup>93</sup>, the Crisis Rating Scale<sup>94</sup>, the Color-Risk Psychiatric Triage Scale<sup>134</sup>, the Crisis Triage Rating Scale<sup>94</sup>, the Triage Assessment Form<sup>95</sup>, and the Crisis Risk and Adaptive Functioning Tool<sup>97</sup>. The main drawbacks of these scales is their narrow focus on suicidality as the precipitating psychiatric event as well as their reliance on clinician administration, which limits the measure's use in epidemiologic research due to the costs of conducting clinical assessments in large populations. Most importantly, none of these measures were designed for youth, in general, or specific populations who may be at greatest risk for crisis, namely those with ASD.

Recently, Weiss and Lunsy explored the measurement of crisis among families raising a child with ASD<sup>98-100</sup>. Their qualitative work suggested that parent's conceptualized crisis across four themes: 1) the child's behavioral problems and difficulty with service providers, 2) the deleterious effects of crisis on the family, 3) frequent use of emergency services for crises, and 4) the parent's need for social and professional support to manage crisis-related events. These themes informed the development of the Brief Family Distress Scale (BFDS)<sup>100</sup>, a single item rating that considers the global or overall state of the family as it relates to crisis. Their data



show that the BFDS is positively associated with a host of adverse outcomes including negative life events, financial problems, poor quality of life, and the child's problem behavior. The BFDS differs from previous crisis measures because it focuses on availability of family resources versus psychopathology (e.g., suicidality) as the precipitant of crisis.

Taken together, there is a shortage of instruments that capture whether youth with ASD are at risk for or are currently experiencing a mental health crisis. The goal of this study was to present psychometric data on a novel crisis measure for youth with ASD that was developed by a group of clinicians and researchers with expertise in the management of co-occurring psychopathology in this population. The specific aims of this study were to: 1) describe the development of the Mental Health Crisis Scale (MCAS), 2) examine the reliability as well as the construct, criterion, and concurrent validity of the MCAS, and 3) assess differences in the psychometric performance of the MCAS between youth (6-17 years) and young adults (18-25 years).

## **4.2 Methods**

### **4.2.1 Sample and Inclusion Criteria**

Data for this study were collected from the Interactive Autism Network (IAN), the nation's largest online ASD research effort. IAN includes more than 10,000 children with ASD and over 20,000 of their family members. Families enrolled in IAN have contributed data via standardized and custom forms. Data include basic demographic variables and results from widely used ASD screening tools such as the Social Communication Questionnaire Scale (SCQ) <sup>135</sup>. Prior studies have validated the ASD diagnosis among IAN participants through medical record review and/or

direct observation using the Autism Diagnostic Observation Schedule<sup>136,137</sup>. Children with ASD and a score of  $\geq 12$  on the SCQ were included in this study.

There were two waves of data collection in this study. Data from the first wave ( $n = 229$ ) were gathered from parents to examine the psychometric properties of the initial version of the MCAS. A subgroup ( $n = 121$ ; 53%) of these parents participated in the clinician assessment to validate the measure (as described below). Results from these analyses informed changes in the MCAS, which was launched in its final form during the second wave of data collection ( $n = 377$ ). Participants who completed the study protocol, which included the clinical interview, in the first wave of data collection received a \$20 Amazon gift card. Participants in the second wave of data collection were entered into a raffle for an iPad. Parents could only participate in one wave of the study. The total response rate across both waves of the study was 10%.

The average age of the sample was 13.5 years old ( $SD = 4.6y$ , range 3 to 25 years) of which 115 of the subjects were between 18 and 25 years of age. Most participants were male (83%), white (85%), and non-Hispanic (94%). For the respondent, nearly all (98%) were the youths' mother, who were, on average, 44.8 years of age ( $SD = 7.9 y$ ) and well educated (7% high school only, 31% had some university or trade school experience, 35% received their bachelor degree, and 28% had some post-graduate education).

The legal guardian, who was usually the parent, was the sole informant for both children and young adults. All guardians filled out an online consent form before completing the MCAS. Respondents were provided with a national crisis hotline number to contact if they became

concerned about their child's behavior at any point during the study. This study was approved by the local institutional review board.

#### 4.2.2 Measures

##### 4.2.2.1 The Mental Health Crisis Assessment Scale (MCAS)

###### 4.2.2.1.1 Defining the conceptual model

The development of the MCAS was guided by the Patient-Reported Outcomes Measurement Information System (PROMIS®) <sup>138</sup>, which represents the National Institute of Health's consensus guidelines for the development and evaluation of psychometric instruments. The MCAS was initially developed by convening a multidisciplinary group of clinicians and researchers to discuss various conceptual models of mental health crisis based on the prior literature. The group was comprised of experts in child and adolescent psychiatry, behavioral psychology, social work, and public health. During this meeting, a consensus definition of mental health crisis was established, which was comprised of two important constructs from the APA Task Force Definition of a psychiatric crisis<sup>22</sup>: 1) the presence of acute psychiatric symptoms in the child with ASD and 2) the parent's perceived ability to manage those symptoms. The expert panel also agreed that the parent's ratings of acuity should correspond to the most dangerous behavior that their child was exhibiting. This approach is similar to other scales such as the Challenging Behavior Interview, a measure of externalizing behaviors for children and adults with intellectual disability <sup>139</sup>. In theory, having the parent report on the single most dangerous behavior sets a ceiling for the crisis score.

#### 4.2.2.1.2 Design of item pool and field testing

Items were designed using the recommendations put forth by the PROMIS® guidelines<sup>138</sup>. Before the study was launched, pilot data were gathered from ten parents who indicated that the questions were clear, comprehensible, and did not induce distress. The Flesch Kinkaid reading level was 8.6, which is consistent with a middle school reading level.

The final scale was a 28-item parent report measure (see Appendix Figure 1) comprised of three sections. The first section is a 14-item list of various mental health behaviors seen in ASD. Parents are asked to rate the severity of each behavior within the last 3 months on a 4-point Likert scale, ranging from “Not a problem” to a “Severe problem”. The second section consists of one question only, which asks parents to identify “the single behavior that could cause the greatest harm to your child or others” from the 14 items listed in Section 1. Section 3 consists of 13 questions that asks parents to report their concerns about the dangerousness of the child’s behavior to self and others (termed “acuity”; items 1-8) as well as their ability to manage this behavior (termed “behavioral efficacy”; items 9-13). All items in Section 3 are reported on the single most difficult behavior identified in Section 2. For example, if parents indicated that aggression was the most harmful behavior in Section 2, then all questions in Section 3 were focused on the acuity of the aggression and the parent’s ability to manage it. Response options for the acuity and behavioral efficacy were based on a 3-point Likert scale, ranging from “Never/Rarely” to “Frequently” for the acuity subscale and “Disagree” to “Agree” for the behavioral efficacy subscale. Items 9, 11, and 13 are reverse scored. Higher MCAS scores represent a greater probability of a mental health crisis.

It is worth noting that the MCAS was initially designed as three constructs: acuity, behavioral efficacy, and resources. The resources component focused on the availability of professionals to assist parents with their child's behavior. These questions were removed because none of these items were related to clinician determination of crisis during the criterion validity study. This was likely because parents who reported the highest crisis scores frequently reported the greatest number of professionals involved in their child's care due to the underlying severity of the child's condition. This finding, which is similar to concept of confounding by indication or confounding by severity, could lead to confusion during scoring. Furthermore, after review of the clinician interview data, it was evident that clinician decision making was not based on the presence of external resources. Rather, determination of crisis was predominately based on the acuity of the individual's behavior and partially related to the parent's ability to manage these events themselves.

#### 4.2.2.2 Clinician assessment of crisis

The purpose of the clinician interview was to examine the level of agreement between the MCAS and clinician assessment of a mental health crisis. A custom, semi-structured clinician interview was developed and administered to the parent by phone to a subgroup in wave 1 of the study. Clinician opinion was considered the criterion variable for the presence of a mental health crisis since psychiatric interview is the gold standard for establishing a diagnosis.

The clinician interview was similar to the MCAS and gathered information about the various types of behaviors exhibited by the child, the most dangerous of these behaviors, the use of emergency services, and the parent's ability to manage the child's behavior. The clinician also

asked about the presence of suicidality and elopement since these two behaviors were deemed especially high risk given their potential for severe injury or death. This information, combined with the clinician's acumen, were used to classify the individual as being at "low" or "high" risk of crisis. All clinicians were blinded to the individual's MCAS score.

Three clinicians with at least four years of experience working with youth with ASD and severe mental health problems conducted the phone interviews. Agreement between raters on 10 training vignettes was excellent ( $\kappa = 0.86$ ). The median time between completing the MCAS and the clinician interview was 12 days (mean days = 16.5, SD = 14). No difference in agreement was found for interviews that took place less (ROC = 0.82, 95% CI; 0.72-0.93) or more than (ROC = 0.91, 95% CI; 0.80-0.99) 12 days of MCAS completion.

#### 4.2.2.3 Additional Assessments

Three additional measures were conducted to evaluate convergent validity. The Brief Family Distress Scale (BFDS) is a single item that asks parents "where they and their family members are, right now, in terms of crisis" <sup>99</sup>. On a scale of 1-10, responses range from "Everything is fine, my family and I are not in crisis at the moment" to "We are currently in crisis, and it could not get any worse". The BFDS has demonstrated convergent validity through its association with parental coping and adjustment as well as family stressors <sup>99</sup>. The Parental Aggravation Index (PAI) was employed as a measure of stress and frustration that parents experience while caring for their child <sup>140,141</sup>. The PAI is comprised of four items from the Parenting Stress Index and the Child-rearing Scale, including: 1) feeling that it was harder to care for their child than others of the same age, 2) the child doing things that really bothered them, 3) feeling angry with the child,

and 4) feeling that the parent gave up more of their life than expected to meet the child's needs<sup>141</sup>. Cronbach's alpha for the four item scale in the present study was 0.77, which is substantially higher than what is reported in the original development sample ( $\alpha = 0.63$ ). The PAI has demonstrated construct validity through its association with factors known to relate to caregiving stress, including decreased household income and parental level of education<sup>141</sup>. Finally, parents were asked about the use of emergency psychiatric services to help manage their child within the last 3 months. This included questions about: 1) calling 911 or the police, 2) an emergency department visit, or 3) an inpatient hospitalization. This variable was dichotomized and coded as 1 if the parent reported use of any of these services and 0 if not.

#### 4.2.3 Statistical Analysis

The MCAS items submitted for psychometric assessment were from Section 3 (acuity and behavioral efficacy subscales). The mental health symptoms and behaviors listed in Section 1 were not psychometrically examined because this section was considered an index, not a scale<sup>142</sup>. Exploratory factor analyses (EFA) and confirmatory factor analyses (CFA) were conducted in MPLUS 7.0 using the categorical option given the observed items from the MCAS were ordinal<sup>143</sup>. All other analyses were performed in STATA 12.0<sup>144</sup>. Overall, there was little missingness (<5% of any item was missing data).

##### 4.2.3.1 Construct Validity and Factor analyses

To determine the factor structure of the MCAS, EFA was performed in the first wave of data collection. The EFA took place using the 5 step procedure recommended by Costello and Osborne<sup>145</sup>. After revising the measure based on the findings from the EFA, confirmatory factor

analysis (CFA) was used in the second wave of data collection to evaluate the factor structure using fit indices<sup>146</sup>. These included root mean square error of approximation (RMSEA), the comparative fit index (CFI), and the Tucker-Lewis index (TLI). A CFI and TLI of  $\geq 0.9$  is considered an acceptable fit, whereas  $\geq 0.95$  reflects a good fit, and  $< 0.10$  for RMSEA is considered a good fit<sup>147,148</sup>.

#### 4.2.3.2 Reliability

Reliability was assessed via Cronbach's alpha and item-rest correlations. These analyses were employed in the first and second wave of data collection.

#### 4.2.3.3 Criterion validity

Criterion validity was determined by examining the relationship between the MCAS and the clinician overall crisis rating using three statistical measures: 1) sensitivity, 2) specificity, and 3) the Receiver Operator Score (ROC) score<sup>149</sup>. A crisis algorithm was then developed based on those items with the highest ROC values.

#### 4.2.3.4 Convergent validity

The relationship between the MCAS, the PAI, and BFDS were assessed using a Pearson's correlation coefficient. Use of emergency psychiatric services (911/police, ED, or hospital) and meeting the MCAS algorithm cutoff was assessed using logistic regression.



#### 4.2.2.3.5 Psychometric performance of the MCAS in children vs. young adults with ASD

All of the analyses were repeated to examine the effects of age (ages 3-17 years versus 18-25 years) on MCAS scores. However, the EFA was not tested for young adults due to insufficient sample size. Instead, the CFA was fit separately for youth vs. young adults on the combined sample (from study waves 1 and 2) to provide as much data as possible on young adults.

### 4.3 Results

#### 4.3.1 Exploratory Factor Analysis

Exploratory factor analysis (EFA) was first employed to determine the number of factors present in Section 3 of the MCAS. Results from the Bartlett test of sphericity ( $\chi^2 = 1306$ ,  $p < 0.001$ ) and the Kaier-Meyer-Olkin measure of sampling adequacy ( $KMO = 0.887$ ) both supported the suitability of the correlation matrix for EFA procedures. The initial EFA procedure examined the model fit of 17 total items. One item from the acuity subscale and three items from the behavioral efficacy subscale were removed due to poor factor loadings ( $< 0.40$ ). After removal of these items, which resulted in a total of 13 items remaining in Section 2 for the final version of the MCAS, a 2 factor solution (factor 1: acuity, factor 2: behavioral efficacy) appeared to best fit the data. This was based on the eigenvalue (EV) sharply dropping below 1 after the second factor (Factor 1 EV = 5.1; Factor 2 EV = 1.3; Factors 3 and below  $< 0.4$ ) and the difference between the factor analysis and parallel analysis eigenvalues was large for only the first two factors (Difference in PA vs. EV for Factor 1 = 4.8, Factor 2 = 1.1, and Factors 3 and below  $< 0.3$ ). Seventy nine and twenty percent of the total variance was explained by the first and second factors, respectively. Loadings from the EFA are shown in Table 2.

#### 4.3.2 Confirmatory Factor Analysis

Results from the confirmatory factor analysis supported the fit between the 2 factor model and the observed data. This can be seen in the high factor loadings ( $>0.65$ ) for all items except item number thirteen, and adequate (RMSEA = 0.10) to excellent (CFI = 0.96 and TLI = 0.95) fit statistics. The acuity and behavioral efficacy factor scores were positively correlated ( $r = 0.57$ ,  $p < .001$ ).

#### 4.3.3 Reliability

Table 1 displays the alpha and item-rest coefficients from waves 1 and 2. Alpha values were similar across waves for the acuity (wave 1,  $\alpha = 0.87$ ; wave 2,  $\alpha = 0.89$ ) and behavioral efficacy (wave 1,  $\alpha = 0.80$ ; wave 2,  $\alpha = 0.80$ ) subscales. The same pattern was found for the overall scale as well (wave 1,  $\alpha = 0.88$ ; wave 2,  $\alpha = 0.88$ ).

#### 4.3.4 Criterion Validity

Criterion validity was established by examining the relationship between the MCAS and clinician determination of crisis. Clinicians determined that 68% of youth who participated in the clinician interview were deemed to be “at risk of crisis”. ROC values for each item from Section 3 of the MCAS are in Table 2. To construct the crisis scoring algorithm, each item from the MCAS was iteratively summed and tested until the optimal ROC value or j-point was found. Once the optimal algorithm was identified using items from Section 3, two items from Section 1 (suicidality and elopement) were added to the algorithm score since these items were incorporated into the clinician determination of crisis. The optimal scoring algorithm included summing items from Section 3 (1, 4-8, and 11-13) with the weighted (by a factor of 3) sum of

items 5 and 9 from Section 1 (see Figure 1 for details). The overall ROC score (ROC = 0.85) was excellent. The optimal cutoff was a score of  $\geq 18$ , which resulted in a ROC score of 0.78, 82% sensitivity, 74% specificity, 79% of cases correctly classified, positive predictive value of 87% and negative predictive value of 66%. Overall, 40% of the entire sample met the crisis cutoff on the MCAS. Directions for scoring are shown at the bottom of Figure 1.

The distribution of the MCAS crisis scores are shown in Figure 2. The crisis score ranged from 5 to 30 (Mean = 11.7, Median = 11.7, SD = 5.3) in this sample. The distribution was negatively skewed. This is due, in part, to the fact that most of the scores were in the lower bound of the score range (e.g., 14% of the sample had the lowest possible score of 5).

#### 4.4.5 Convergent Validity

Convergent validity was established by examining the association between the MCAS, PAI, BFDS, and use of emergency psychiatric services. All three scores from the MCAS (the crisis algorithm,  $r = .57$ ; acuity subscale,  $r = .54$ ; and, behavioral efficacy subscale,  $r = .53$ , all  $p < 0.001$ ) were positively associated with the BFDS; a similar finding was observed for the PAI (the crisis algorithm,  $r = .48$ ; acuity subscale,  $r = .49$ ; and, behavioral efficacy subscale,  $r = .45$ , all  $p < 0.001$ ). The MCAS was also useful for identifying parents who reported using emergency psychiatric services in the last 3 months ( $n=57$ ). More specifically, an MCAS score of  $\geq 18$  was able to correctly identify 93% of parents who reported use of these services. In the logistic model, parents who reported an MCAS score of  $\geq 18$  were 24 times more likely to use emergency psychiatric services compared to those with an MCAS score of  $< 18$  (OR = 24.2, 95% CI: 8.6 – 68.2).

#### 4.4.6 Psychometric Performance of the MCAS in Youth vs. Young Adults with ASD

No difference was found in the internal consistency values between age groups (youth, ages 3-17,  $n = 452$ ; young adults, ages 18-25,  $n = 115$ ) for the acuity subscale (youth,  $\alpha = 0.88$ ; young adults,  $\alpha = 0.88$ ) or behavioral efficacy subscales (youth,  $\alpha = 0.81$ ; young adults,  $\alpha = 0.79$ ) from the MCAS. Associations between the acuity (youth,  $r = 0.54$ ; young adults  $r = 0.63$ ), behavioral efficacy (youth,  $r = 0.51$ ; young adults  $r = 0.54$ ), and MCAS crisis score (youth,  $r = 0.56$ ; young adults  $r = 0.56$ ) with the BFDS were similar. The same associations were present between the acuity (youth,  $r = 0.49$ ; young adults,  $r = 0.49$ ), behavioral efficacy (youth,  $r = 0.45$ ; young adults,  $r = 0.43$ ), and MCAS crisis score (youth,  $r = 0.49$ ; young adults,  $r = 0.45$ ) with the PAI. Lastly, use of emergency psychiatric services and the MCAS crisis score for those less than 18 years of age ( $OR = 29.9$ , 95% CI: 7.0-126.7) compared to those 18-25 years of age ( $OR = 33.3$ , 95% CI: 3.9-287.4) (all  $p < .001$ ).

When examining levels of agreement between the MCAS and clinician determination of crisis, no difference was found for the accuracy of the MCAS when classifying crises among youth ( $n = 96$ ) compared to young adults ( $n = 24$ ) for the overall crisis score (youth,  $ROC = 0.84$ ; young adult,  $ROC = 0.87$ ) or the crisis cutoff (youth,  $ROC = 0.77$ ; young adult,  $ROC = 0.81$ ). Lastly, results from the CFA procedure supported the fit between the 2 factor model and the observed data among youth ( $RMSEA = 0.10$ ,  $CFI = 0.96$ ,  $TLI = 0.95$ ) and young adults ( $RMSEA = 0.09$ ,  $CFI = 0.97$ ,  $TLI = 0.97$ ). In both samples, the factor loadings were nearly identical to those seen in Table 2.

#### **4.5 Discussion**

Results of this study support the MCAS as an internally sound instrument for assessment of mental health crisis in children and young adults with ASD. Reliability, measured as internal consistency across two independent waves of data collection, ranged from good to excellent. For internal construct validity, exploratory factor analyses identified two factors, perceived acuity and behavioral efficacy, in the first wave of data collection. Confirmatory factor analysis employed in the second wave of data collection confirmed that the two factor model did indeed fit the observed data well. The first factor, which explained most of the instrument's variance, represented the acuity subscale. This factor measured the parent's perceived concerns about the dangerousness of the child's behavior to themselves and others, which is most commonly the reason for inpatient psychiatric hospitalization. The second factor ("behavioral efficacy") assessed the parent's ability to manage the child's acute thoughts, mood, or behavior. These items provide critical information about the level of support required to assist parents in managing an acute psychiatric event involving their child.

Our analyses also showed that the MCAS aligned with other measures of crisis. Results from the ROC analyses demonstrated that the MCAS crisis score had strong classification properties when compared to clinician determination of crisis. Overall, approximately eight of ten children with ASD were correctly classified as in crisis versus not. There was also a moderate positive correlation between the MCAS, the BFDS (a measure of family crisis), and the PAI (a parenting stress and aggravation index). Lastly, more than ninety percent of parents who sought emergency psychiatric services to manage a crisis involving their child met the MCAS cutoff. This association highlights the potential of the MCAS to predict real world decisions that parents must

make when their child is in crisis, which suggests some ecological validity of the measure. With further testing, the MCAS could be used by child psychiatrists, as well as front line providers such as pediatricians, during the first visit with families to identify children in need of immediate intervention.

Results from the psychometric analyses demonstrated that the MCAS performed equally well for children and young adults. Including young adults with ASD was critical given the dearth of mental health measures, services, and treatments designed for this population <sup>150</sup>. There is a tremendous need for mental health services in young adults, many of whom are struggling with severe anxiety, depression, suicidal ideation, and behavioral issues <sup>7</sup>. Transition planning is also a major challenge in this population given the shortage of group homes, day programs and employment opportunities <sup>151</sup>. Decisions about placement often depend on the severity of mental health disturbances. Measurement of mental health crises may help guide best practices around placement and resources required to prevent and maintain safety throughout adulthood.

The predominance of psychometric methods used in the present study were based on classical test theory. As such, future research should look towards employing complimentary psychometric approaches, such as those based on latent trait theory, to generate additional information about the MCAS. Item-response theory, in particular, could provide additional information about the MCAS such as item difficulty, discrimination, reliability, and differential item functioning (DIF). Examining DIF is particularly important since certain MCAS items may perform differently across populations. For example, the acuity items may more accurately detect crisis when parents report on externalizing, rather than internalizing, behaviors. While the

sensitivity analyses performed for young adults versus youth support similar measurement between these age groups, those analyses were generally performed with summed scores. DIF-based analyses, on the other hand, provide a more in-depth examination at the item-level and may reveal biases not discovered among summed scores.

Although the MCAS was specifically designed for those with ASD, future research could consider adapting the MCAS for other pediatric populations since, to our knowledge, no crisis measures exist for youth without ASD. Section 1, which asks parents to rate the severity of a variety of mental health problems, is the only section that may require modification depending on behaviors specific to other populations. For Section 3, there is no reason to suspect that individual items would function differently among those without ASD. DIF testing, described above, should be employed to confirm or deny this hypothesis.

Lastly, we hope the MCAS can ultimately be used in clinical practice but do not believe this study alone warrants its dissemination into treatment and referral settings. To move this measure to practice, there must be direct evidence for the benefits of crisis screening using the MCAS, such as increased treatment referral rates and uptake of such treatments, when compared to those who are not screened, and improved short and long term functional outcomes with treatment for those identified through the screening process.

There are several strengths and limitations of this study. Large sample sizes gathered over two waves of data collection is an important strength since this allowed for replication of the reliability and factor analytic findings. Examining clinical levels of agreement with the scale is

considered another strength of the study. Particularly notable is that the MCAS is based on parent- rather than clinician- report, which allows for assessing the epidemiology of mental health crises among populations in a cost-effective manner. As for limitations, data from this study are not representative of children with ASD as a whole since they were gathered from a convenient sample. Another concern related to selection bias was the low response rate. This may have resulted in an over- or under-reporting of symptoms, although which direction is unclear. Lastly, future studies should consider providing further evidence of convergent validity for the MCAS. Investigating the relationship between mental health crisis and psychiatric diagnosis is particularly warranted.



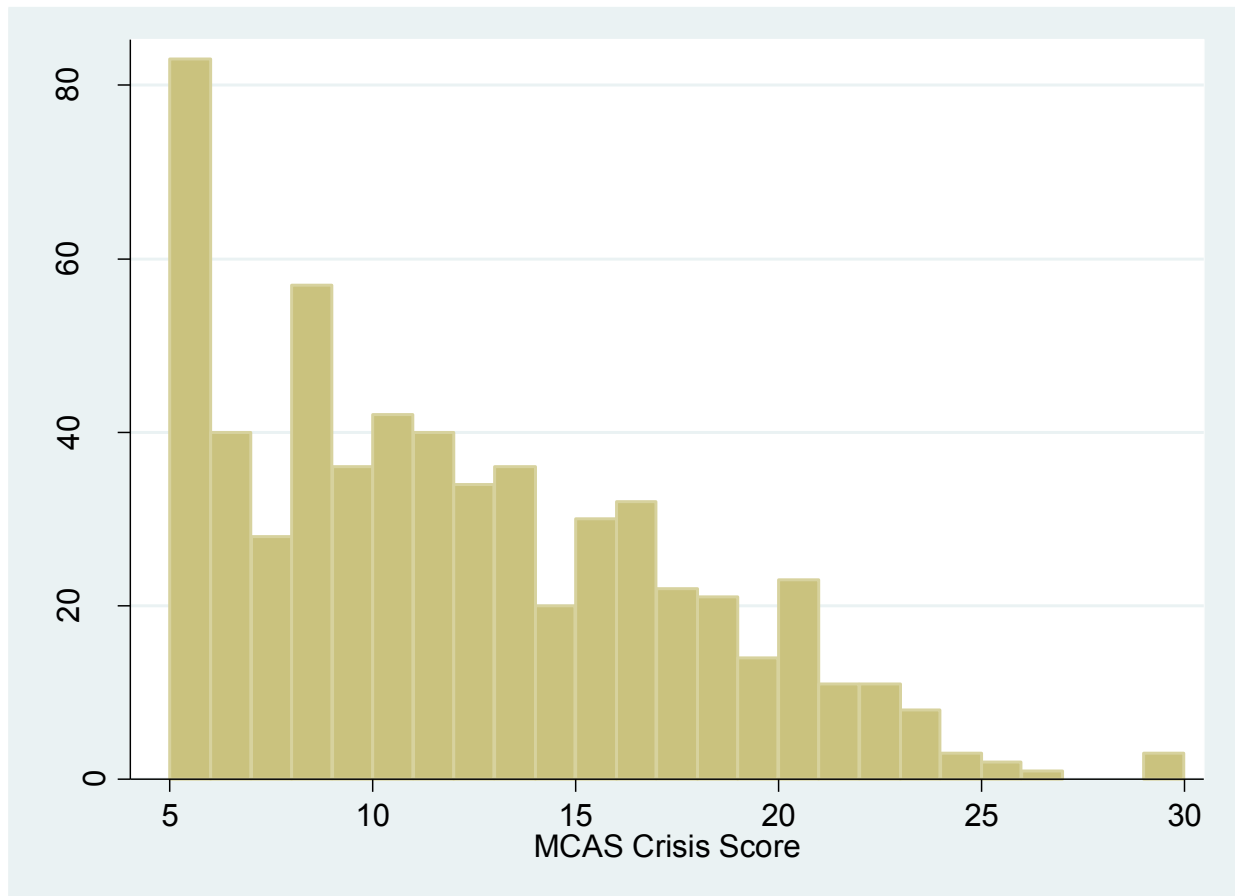
Chapter 4: Table 1, Internal Consistency of the MCAS

	Wave 1 (n=229)		Wave 2 (n = 377)	
	Item-rest correlation	Alpha	Item-rest correlation	Alpha
My safety	0.46	0.88	0.54	0.89
Immediate intervention	0.53	0.87	0.65	0.88
Professionals	0.69	0.85	0.73	0.88
Danger to Self	0.72	0.85	0.73	0.87
Nervous	0.71	0.85	0.76	0.87
Alarmed	0.72	0.85	0.73	0.87
Risk to Others	0.52	0.87	0.59	0.88
Family/friends worried	0.71	0.85	0.66	0.88
Deal with behaviors myself	0.47	0.79	0.44	0.80
Need help	0.64	0.74	0.66	0.73
Effectively handle	0.64	0.74	0.61	0.75
Too much	0.70	0.72	0.67	0.72
Coping well	0.46	0.80	0.50	0.78

Chapter 4: Table 2, Factor Loadings and ROC Values of MCAS Items

Item	Exploratory Factor Analysis* (n = 229)		ROC values* (n = 121)	Confirmatory Factor Analysis** (n = 377)
	Acuity	Behavioral Efficacy	-	-
My safety	0.59	-0.01	0.70	0.69
Immediate intervention	0.55	0.19	0.60	0.77
Professionals	0.70	0.17	0.67	0.84
Danger to self	0.93	-0.02	0.75	0.92
Nervous	0.96	-0.06	0.73	0.92
Alarmed	0.78	0.13	0.72	0.88
Risk to others	0.58	0.13	0.65	0.74
Family/friends worried	0.77	0.13	0.70	0.82
Deal with behaviors myself	-0.20	0.78	0.54	0.50
Need help	0.04	0.86	0.69	0.83
Effectively handle	-0.07	0.86	0.60	0.72
Too much	0.16	0.82	0.66	0.95
Coping well	0.12	0.57	0.65	0.77
* Data was from wave 1, ** Data was from wave 2				

Chapter 4, Figure 1: Distribution of MCAS Crisis Scores



Chapter 4, Figure 2: The Mental Health Crisis Assessment Scale (MCAS)

Date Completed: \_\_\_\_\_

Age of Child (in years): \_\_\_\_\_

**Section 1:** Please rate the following behaviors for your child **over the past 3 months**. The behaviors are listed in the first column and examples of those behaviors are listed in the second column.

Behaviors	Examples of Behaviors	Not a problem	Minor problem	Moderate problem	Severe problem
1. Injures or hurts <u>self</u>	Bangs head, bites self, hits self with object, picks skin	0	1	2	3
2. Physically aggressive <u>towards others</u>	Hits, kicks, pushes, spits , or grabs others	0	1	2	3
3. Verbally aggressive <u>towards others</u>	Yells, screams, curses, threatens	0	1	2	3
4. Destroys property	Breaks furniture, puts holes in wall(s), damages his/her toys or games	0	1	2	3
5. Elopes	Runs away, suddenly wanders	0	1	2	3
6. Dangerously impulsive	Suddenly grabs steering wheel, inserts object into electrical outlet	0	1	2	3

7. Unhappy	Crying, gloomy, sad, feelings of hopelessness, not interested in usual activities	0	1	2	3
8. Nervous	Fearful, worried, tense, panicky, clingy, anxious	0	1	2	3
9. Suicidal thoughts or behaviors	Has expressed or attempted to end his/her life, thoughts of death	0	1	2	3
10. Tantrum(s)	“Blows up”, explosive outbursts, rage	0	1	2	3
11. Disobedient	Does not comply with demands, oppositional, defiant, manipulative	0	1	2	3
12. Loss of touch with Reality	Paranoid or some other odd/unusual fixed belief, sees or hears things that aren’t there	0	1	2	3
13. Sudden, worrisome change in behavior, mood, or thinking	Decreased daily functioning; change in sleep, energy, concentration, etc.	0	1	2	3
14. Eating non-food items	Eating crayons, dirt, or other non-food objects (also known as PICA)	0	1	2	3

**Section 2:** This section will ask you about the dangerousness of your child’s behavior. To complete this section, we would like you to **circle a single behavior** below that that could cause the greatest harm to your child or others in the last 3 months. Please review your responses from Section 1 when making your selection below.

Injures or hurts <u>self</u>	Physically aggressive <u>towards others</u>	Verbally aggressive <u>towards others</u>
Destroys property	Elopes	Dangerously impulsive
Unhappy	Nervous	Suicidal thoughts or behaviors
Tantrum(s)	Disobedient	Loss of touch with Reality
Sudden, worrisome change in behavior, mood, or thinking	Eating non-food items	

**Section 3:** Now, please answer the questions below in relation to the single behavior that you identified above that could cause the greatest harm to your child or others in the last 3 months. For example, if you circled *Tantrum(s)* in the section above, then all the questions below should be answered in regard to tantrum(s). Again, these concerns should focus only on the **past 3 months**:

Question	Never/Rarely	Sometimes	Frequently
1. I am concerned about my safety when my child acts this way.	1	2	3
2. I felt that my child's behavior(s) needed immediate intervention.	1	2	3
3. Professionals involved in my child's life (such as their teachers or doctors) have expressed their concern about the dangerousness of my child's behavior(s).	1	2	3
4. I felt that my child's behavior(s) posed a risk of danger to him/herself.	1	2	3
5. I am nervous about my child's safety in these situations.	1	2	3

6. Other people have told me that they are alarmed when my child behaves this way.	1	2	3
7. I felt my child's behavior(s) posed a risk to others.	1	2	3
8. My family and/or friends have told me they are worried when my child acts this way.	1	2	3
<b>Please use the following response options for the remaining questions:</b>	<b>Disagree</b>	<b>Neither Agree or Disagree</b>	<b>Agree</b>
9. I would prefer if others would let me deal with these behavior(s) myself.	1	2	3
10. I need someone's help when my child has these behavior(s).	1	2	3
11. I can effectively handle these situations.	1	2	3
12. These behavior(s) are just too much to handle. I need someone's help.	1	2	3
13. All-in-all, I am coping pretty well with my child's behavior(s).	1	2	3

### Scoring Algorithm

**\*\* Please contact study authors (Luther Kalb, luke.kalb@gmail.com; Roma Vasa, rvasa1@jhmi.edu) prior to use of this instrument\*\***

1. In section 1, multiply item number 5 (elopement) by three = \_\_\_\_\_ +
2. In section 1, multiply item number 9 (suicide) by three = \_\_\_\_\_ +
3. In section 3, sum items 1, 4, 5, 6, 7, 8, 11, and 13 = \_\_\_\_\_

Sum the three totals above for the total crisis score = \_\_\_\_\_

A score of  $\geq 18$  represents an increased risk for a Mental Health Crisis

**CHAPTER 5: IMPROVEMENT IN MENTAL HEALTH OUTCOMES AND  
CAREGIVER SERVICE EXPERIENCES ASSOCIATED WITH THE START  
PROGRAM (STUDY 3)**



### 3.1 Background

Intellectual Disability (ID) is characterized by a delay in cognitive and adaptive functioning that is often identifiable in early development<sup>152</sup>. ID is one of the most common developmental disabilities, with prevalence estimates ranging from 1% to 3% of the US population<sup>152</sup>. The impairment due to ID is substantial. For instance, the years of life lost through premature death and suboptimal health due to ID is six times greater than Attention Deficit-Hyperactivity Disorder (ADHD)<sup>153,154</sup>.

One common challenge among those with ID is the frequent co-occurrence of externalizing problems, such as physical and verbal aggression, property destruction, and disruptive behavior<sup>155,156</sup>. Using an epidemiologically-defined sample in the United Kingdom, Emerson (2003) reported a quarter of youth with ID met criteria for a conduct-related disorder; a proportion that was 7 times greater than those without ID<sup>157</sup>. Kats and colleagues (2013) produced similar findings among adults with ID across two nationally representative samples in the US<sup>158</sup>. Addressing mental health problems in this population is critical since the presence of such has been associated with poor social and academic functioning<sup>13</sup>, lower overall quality of life<sup>159</sup>, earlier age at mortality<sup>160</sup>, and use of expensive, restrictive hospital-based psychiatric services<sup>109,161</sup>. These conditions also affect the family as a whole, as mental health problems are a robust predictor of parent stress and distress<sup>162</sup>, impaired family functioning and well-being<sup>163</sup> and decreased family resources (e.g., problems with employment and/or childcare)<sup>164,165</sup>.

Despite these challenges, access to outpatient psychiatric treatment for individuals with ID is limited<sup>166-168</sup>. The dearth of mental health services is partly due to the lack of mental health

professionals trained to treat them<sup>167</sup>. Even when services are available, caregivers describe their experiences with the mental health service system as fragmented, unresponsive, and insufficient<sup>167</sup>. The START (Systemic, Therapeutic, Assessment, Resources, and Treatment) program is specifically designed to address these concerns.

The goal of START is to enhance local capacity, promote the development of least-restrictive life-enhancing services and supports, and provide education as well as training to providers and caregivers. The Center for START Services, located at the University of New Hampshire Institute on Disability/University Center for Excellence in Disability, was founded in 2007 to assist in the dissemination of the START model that was first developed in 1988. The current network of START providers serve individuals across 10 states in the US, with more states in development.

START serves individuals with an Intellectual or Developmental Disability (IDD) and co-occurring behavioral health needs. In the START Information Reporting System (SIRS), a national database which now includes data on over six thousand individuals who have been served by START since 2012, more than a quarter of those enrolled in START experienced a psychiatric hospitalization in the year prior to their enrollment<sup>169</sup>. About one third of START enrollees have an ASD diagnosis and 70% have mild or moderate ID. Twenty percent have a psychosis-related diagnosis and the most common reason for enrollment is aggression (80%). Slightly fewer than half live with their family members, most are adults, and a third are African American/Black.

Two previous studies have shown promising outcomes for START, including a reduction in healthcare costs, emergency psychiatric service use, and an improvement in service experiences<sup>130,170</sup>. However, these studies took place in the early stages of START before the service model was refined. The present study provides an up-to-date review of START, including data on novel outcomes using a larger sample size across several regions. More specifically, the goal of this study was to examine one year pre-post changes in: a) caregiver evaluation of service experiences, b) the individual's challenging behaviors, and rates of c) psychiatric hospitalizations and d) psychiatric emergency department visits.

Based on prior research, we hypothesized that a trend toward improvement would be observed among mental health symptoms and caregiver services experiences as well as a reduction in urgent psychiatric service use. However, given the known difficulty in making systemic changes, we expected the changes in the use of urgent psychiatric services and caregiver service experiences to be small.

## **3.2 Methods**

### **3.2.1 The START Program**

START is an evidence-informed model that includes a community of practice for evidence-based interventions and fidelity requirements. Methods employed in the model aim to enhance expertise and partnerships across systems in order to provide effective community-based support for individuals with IDD and co-occurring behavioral health needs. This includes linking all START programs through data collection, reporting and the application of START practices. More information about START can be found here:

<http://www.centerforstartservices.com/default.aspx>.

### 3.2.2 SIRS database

All START Clinical Team members are required to submit data SIRS. The purpose of this online data collection system is to evaluate the implementation, fidelity, and effectiveness of START programs that are located throughout the country. Training to accurately enter data into SIRS is provided and the accuracy and frequency of data entry is closely monitored by the Center for START Services, where SIRS is housed. All information entered and extracted from SIRS is fully de-identified and was used for the present study. This study was deemed exempt from human subjects research, by the governing institutional IRB, given the data were gathered during routine care and were absent of identifying information during the analysis.

### 3.2.3 START Clinical Team Services and START Coordination

This study reviews outcomes associated with START Clinical Team Services, the foundation on which the START model is built. All START programs have a Clinical Team that is made up of, at minimum, a director (a master's level clinician), medical director (psychiatrist), clinical director (doctoral-level psychologist), clinical team leader (a master's level clinician) and master's level START Coordinators who carry caseloads of service recipients. Once Clinical Teams consistently meet programmatic fidelity to the START model, they all apply to become certified through the Center for START Services. When certification is obtained, Clinical Teams remain in the Network and receive ongoing training and support as well as regular quality reviews from the National Center for START Services. The START Clinical Teams reported on in this study were newly founded. They were chosen to provide a more up-to-date

review of START outcomes and because enrollment trends for new programs allow for capturing a cohort of families who enter START at similar times.

START Clinical Teams develop and maintain linkage agreements with local providers and service systems that are used by START Coordinators to assist in their daily practices. The purpose of these agreements is to promote cross-system collaboration, clarify roles and responsibilities, and identify as well as overcome existing barriers in the system. START Clinical Teams operate 24 hours a day, 7 days a week, including crisis evaluation and support services.

START Coordinators receive national certification from the Center for START Services upon completion of extensive training. A central component of work for START Coordinators is to develop an integrated understanding of the individual and his/her needs. This knowledge, along with input from other members of the START Clinical Team, is used to conduct comprehensive service evaluations that assess the needs of the individual and their natural as well as formal supports. All members of the Clinical Team, including START Coordinators, are highly trained and experienced in serving individuals with IDD and co-occurring mental disorders and/or challenging behaviors. In this study, two of the teams are “lifespan” teams and serve individuals from age 6 and older. One of the teams is an “adult” team and provides services to adults 18 years of age and older.

#### 3.2.3.1 Crisis Prevention and Intervention

START Clinical Teams provide 24-hour mobile crisis prevention and intervention services. The

primary tool to assist caregivers and first responders is the START Cross System Crisis Prevention and Intervention Plan (CSCPIP). The CSCPIP is an individualized written plan of response to provide a clear, concise, and realistic set of supportive interventions to prevent or de-escalate a crisis. The goal of the CSCIP is to build the capacity of primary caregivers to address vulnerabilities in the person's setting through the identification of individual character strengths and effective strategies in early stages of difficulty. The plan offers a tertiary level of response that ranges from early intervention to assisting during an acute crisis. All CSCPIPs are developed and implemented by START Coordinators in collaboration with the person's system of support. Ninety one percent of all individuals in this study had a completed CSCPIPs (mean hours of crisis planning and collaboration with the primary system of care = 9.5).

START employs 24 hour crisis evaluation and response services. Emergency calls come from a variety of sources such as emergency departments, community providers, families, and law enforcement. Adherence to the model requires immediate telephonic response and in-person evaluation within two hours of the initial contact. In this study, 40% of all individuals were involved in a crisis evaluation (Mean evaluations per individual during the study period = 3.0).

#### 3.2.3.2 Outreach

Outreach involves any non-emergency contact made with the individual or their system of support. Examples include home and school-based visits to observe the individual in their daily setting, visiting the family home to help a parent implement a plan or strategy, and checking in with the individual to assess their level of stability. In this study, 96% of individuals received outreach (Mean Hours of Outreach during the study period = 11.1)

### 3.2.3.3 Medical/Psychiatric Consultation Services

Clinical consultation services are available to all START members and their network. These services are often delivered by the START medical and/or clinical director and include, but are not limited to, diagnostic assessment, medication review, medical or psychiatric follow-up, and consultation with the individual's outpatient providers. Sixty three percent of individuals in this study received Medical/Psychiatric Consultation Services (Mean Hours of Clinical Evaluation during the study period = 2.7).

### 3.2.4 Inclusion Criteria and Sample Characteristics

The present study has four inclusion criteria. First, the person must have a diagnosis of a developmental or intellectual disability. The presence of such is usually required by states for funding of START services. Second, the individual must live with a family caregiver, rather than in a group home or a supported setting. Caregivers were the sole informant in this study since residing with family members is the single most common setting for those served by START and these caregivers are relied upon to access services and supports for the individual. This is particularly true for youth; a population that is increasingly being served by START. Third, the participant must have a state-funded ASD and/or ID waiver or receive SSDI (Medicaid) insurance since this is the funding mechanism for receipt of START Clinical Team services. Fourth and finally, the individual must be enrolled in START for at least six months. Six individuals who were enrolled on average for 2 ½ months were therefore removed.

Data for this study were gathered from caregivers of 111 individuals with IDD, between 2014 and 2016, from four START Clinical Teams that were providing services in two states located in the southwestern ( $n = 14$ ) and northeastern ( $n = 96$ ) US. These sites were chosen because they Fifty seven of the participants were youth (Mean age = 14y, Min = 6y, Max =17y) and fifty three were adults (Mean age = 27, Min = 18y, Max =61y). Most of the subjects were male (71%), had mild ID (44%; 26% moderate ID, 13% severe/profound ID), and were white (84%). More than half of the sample were diagnosed with Autism Spectrum Disorder (ASD; 58%) and most had a diagnosed co-occurring psychiatric disorder (63%; Mean diagnoses = 1.3). Slightly fewer than half of the sample (42%) were diagnosed with an internalizing disorder (i.e., depression, anxiety, or adjustment disorder), 35% were diagnosed with an externalizing disorder (i.e., impulse control disorder, ADHD/ADD), and 26% received a psychosis-related diagnosis (i.e., schizophrenia, psychotic or bipolar disorder). All diagnoses were obtained via chart review. For the informant, most were parents (84%), female (91%), married (69%), had a high school degree (37%; 28% some college, 35% college graduate), and were, on average, 48 years of age ( $SD = 10.5$  y).

### 3.2.5 Measures

#### 3.2.5.1 Perceived Quality of Mental Healthcare

Caregivers perceived support from and attitudes towards the mental healthcare system was assessed via the Family Experiences Interview Schedule (FEIS), a semi-structured interview<sup>171,172</sup>. The FEIS was chosen since it directly aligns with and measures the primary goal of START: to improve access, appropriateness and accountability of the mental health service system. A total of 20 likert-based items were gathered from the FEIS across three subsections of the Global Evaluation of Mental Health Professionals (GEMHP) subscale. Specifically, 9 items



from the first subscale assessed how family members appraised their own involvement as partners in treatment for their dependent. These items, which solely focused on mental health providers, covered topics such as whether the caregiver received enough information about “what to do” or “who to call” if there was a crisis, their dependents “illness”, and whether providers “responded to the caregivers concerns” or “recognized their burdens”. Responses are based on a 4-point Likert format (“All that was wanted/needed”, “Some, but not as much as I wanted/needed”, “Very little”, and “Not at all”).

The second subscale included 7 items that examined the perceived quality of services provided directly to the respondents’ dependent. Items from this subscale assessed issues such as the ability of the caregiver to “choose between different service options” and “providers” as well as whether services were “flexible enough to meet their needs” or “convenient to use”. The final 4 items from the third subscale examined beliefs about how well the mental health system responds to the needs of the caregivers. Items from this subscale examined if the mental health system “responded to the wishes of the family members”, “how much say the caregiver had about the required services”, and their “level of satisfaction about their role in their family member’s treatment”. All items from the FEIS are shown in Table 1.

The FEIS used in this study was slightly altered from its original form to fit the study objectives. This included changing the reporting period to the past year, due to the study design, and dropping items 2-4, 8, and 12 on the second subscale since those items were not related to mental health services. Previous research across multiple samples have shown the GEMHP to be reliable (Cronbach’s  $\alpha = .92$ ) and internally valid<sup>171</sup>. In this sample, the internal consistency of the FEIS

was similar (Cronbach's  $\alpha = .93$ ) to those previously reported in the FEIS manual<sup>171</sup>. Baseline FEIS interviews took place with the START coordinator. Follow-up interviews were conducted by an individual who was not involved in the program or the family's care. Each interview took approximately 20 minutes to complete.

#### 3.2.5.2 Problem Behaviors

The community version of the Aberrant Behavior Checklist (ABC) was used to measure the presence of challenging behaviors. The ABC is a heavily cited and psychometrically sound measure of psychiatric symptoms for both adults and youth with ID<sup>173</sup>. The ABC consists of 40-items across five subscales. Three of the five subscales – the Irritability, Lethargy, and Hyperactivity subscales – were employed in this study. The Stereotypic and Inappropriate Speech subscales were omitted since they are more closely related to autism symptomatology, such as stereotypies and echolalia, than mental health or challenging behaviors.

ABC scores were collected at the time of enrollment and at follow up (one year later). There were a few instances where an additional follow-up ABC assessment was completed (n=11). When this occurred, the ABC that was closest to the overall sample average, in terms of difference in days between pre and post testing (404 days), was selected. Data on the ABC was available for 82% of the sample (n = 91).

#### 3.2.5.3 Urgent Psychiatric Service Use

Data on urgent psychiatric services, including psychiatric hospitalization and use of the emergency department for mental health purposes or challenging behavior, was gathered

separate from the study interviews. At baseline, informants provided information on use of these services in the year prior to START enrollment. While receiving services, START coordinators cataloged, in real time within the SIRS database, the number of visits an individual had to these settings due to psychiatric or behavioral health reasons. Capturing psychiatric service utilization is part of the routine duties of all START coordinators.

### 3.2.6 Design and Analysis

The present study used a 1 year pre-post design to examine changes in the FEIS, ABC, and urgent psychiatric service utilization from before participation in START to one year following START enrollment. The median time between pre and post interviews was 382 days (Mean= 403 days, SD = 105 days, Min = 196, Max = 715). The difference between pre and post testing for 63% of interviews was  $\geq 365$  days. All pre-testing interviews took place during the START intake or when services began.

Mean pre-post changes in FEIS and ABC scores were analyzed using paired t-tests. To maintain the full sample size for the FEIS, mean imputation at the item level was used since there was some missing data; although it was relatively rare (i.e., only 3 items had  $>7\%$  missingness). The within-person procedure imputed the missing value based on the individual's grand mean from the remaining subscale items<sup>174</sup>. Effect sizes for the FEIS and ABC scores were assessed using Cohen's  $d$ , which is calculated as the differences in means (post – pre) divided by the pooled standard deviation of the pre and post scores. To examine differences in the number of hospitalizations and ED visits between pre and post, the Wilcoxon signed-rank test, a nonparametric test of median differences for matched-pairs, was employed. All analyses were

performed in STATA 11.0 (College Station, Tx) and considered statistically significant at the  $p < .05$  level.

### **3.3 Results**

#### **3.3.1 Perceived Quality of Service Experiences**

Shown in Table 2, significant improvements between from pre to post were observed for each of the FEIS subscales as well as the overall score. For family members evaluations of their involvement with mental health professionals (subscale 1), the average increase in scores between pre and post corresponded to a moderate effect size ( $d = .67$ ). Similar effect sizes were observed between pre and post for the family member evaluations of client services subscale ( $d = .59$ ; subscale 2), the evaluations of system response to family members subscale ( $d = .67$ ; subscale 3) and the total score ( $d = .70$ ; all  $p < .001$ ).

#### **3.3.2 Problem behaviors**

Significant decreases in problem behaviors, between pre and post, were observed for each of the ABC subscales. Also shown in Table 2, effect sizes for the Hyperactivity ( $d = .58$ ), Irritability ( $d = .62$ ), and Lethargy subscales ( $d = .56$ ) were in the moderate range (all  $p < .001$ ).

#### **3.3.3 Urgent Psychiatric Service Use**

During the year prior to START enrollment, 21% and 32% of individuals experienced a psychiatric hospitalization or emergency department visit for mental health or behavioral concerns, respectively. During the study observation period, 11% and 15% of individuals experienced a psychiatric hospitalization or emergency department visit, respectively. Shown in

Table 3, a significant decrease in the median number of visits in a year, between pre and post, was found across both settings (all  $p < .01$ ).

### **3.4 Discussion**

Results from this study showed improvements in caregiver service experiences and problem behaviors of the individual with IDD, as well as a decrease in urgent psychiatric service use, associated with receipt of START Clinical Team services. These data suggest that START Clinical Team services can help to improve outcomes for both the individual within the community, while living with natural supports, for a population at high-risk of institutionalization. These findings also fill an important gap in the literature since mental health services for individuals with IDD have been historically underdeveloped and understudied<sup>175</sup>.

Significant improvement in caregivers' perceived support from and attitudes towards the mental healthcare system was observed between pre and post. Moderate effect sizes were found for each of the FEIS subscales as well as the total score. The effect sizes observed were larger than originally hypothesized. Two of the FEIS subscales focused on similar topics: caregivers' perceived inclusion in their dependents' care and how responsive the mental health system was when they expressed their concerns. All elements of START, especially START coordination and outreach, are designed to include caregivers in their dependents care whenever possible. Significant improvement in the two aforementioned constructs substantiate a primary goal of START: to listen, support, and respond to the person who knows the individual best. These findings also address a known gap in health services research since providers can fail to

prioritize caregiver perspectives and priorities<sup>165,175,176</sup>. This is particularly true for parents raising youth with ASD and has been linked to lower family income<sup>20,80,177</sup>.

The other FEIS subscale examined the perceived quality of services provided directly to the caregivers' dependent. Significant improvements in this subscale suggest START can improve both the access and appropriateness of services. Enhancing the quality of care that is afforded to the individual with IDD - through services such as medical/clinical consultation, crisis planning and intervention, provider education and linkage agreements – is another principle goal of START and a well-known gap for those with IDD<sup>175</sup>.

Improvements in the hyperactivity, lethargy, and irritability subscales of the ABC were observed. Addressing mental health symptoms is important since those with IDD are known to have elevated psychiatric symptomatology compared to the general population<sup>155,158,178</sup>. In fact, these symptoms are the principle reason for referral to START and are a primary reason for caregiver stress<sup>179</sup> and decreased family wellbeing<sup>163</sup>. To put these findings in context with other interventions, the effect sizes observed for both caregiver services experiences and mental health symptoms are tantamount to those observed in recent meta-analyses of wraparound interventions for youth<sup>180</sup> and psychiatric medications<sup>181</sup>. Although, an important difference between this study and those included in the meta-analyses is the present study did not include a control group.

The final outcome assessed changes in urgent psychiatric service use, including hospitalization and emergency department visits. Prior research has shown that the use of both services is elevated among those with IDD<sup>169</sup> and ASD<sup>84</sup>. While hospitalization is an important step along a

continuum of care, this service is expensive, restrictive, and only a few inpatient units are designed for those with IDD<sup>182</sup>. Emergency Department use, on the other hand, offers little to caregivers in terms of treatment. The ED may ultimately be traumatic due to long wait times, use of chemical and physical restraints, and lack of provider knowledge about those with IDD<sup>84,98,106</sup>. Reduction of these visits is, therefore, considered optimal.

Crisis support is an important function of the START program. Prevention of and active support during a crisis are directly targeted by START interventions such as cross systems crisis planning, START crisis response, outreach, and clinical/medical consultation services. The influence of these interventions can be seen in the significant improvements in caregivers knowing who to call during times of crisis, support available during crisis, and assistance on nights and weekends. These findings, alongside a reduction of inpatient admissions and ED visits, are promising in terms of supporting those with the greatest mental health needs.

There are several limitations to the study. First and foremost is the inability to compare the individuals participating in START with individuals who do not, which limits our ability to estimate treatment effects. Use of a control group and inclusion of two or more follow-up periods is an important next step in studying START. Another limitation is a lack of confirmation of diagnosis via standardized measures and expert clinical opinion. A final limitation is the sample was very heterogeneous, including children and adults as well as those with differing levels of ID and ASD. Future research employing larger sample sizes should examine the effects START among these different populations to better understanding if START is more effective for particular subgroups.

Despite these limitations, this study was conducted in a “real-world” setting that provides some measure of ecological validity to the findings. This study also assessed outcomes at the level of the individual, caregiver, and mental health system - across a diverse socioeconomic and geographic sample - over a substantial period of time. Perhaps most importantly, these provide some measure of confidence for positive outcomes among a program, which is rapidly expanding across the country, for a population with great need.

The ultimate goal of the MCAS is twofold ultimately be used in clinical practice but do not believe this study alone warrants its dissemination into treatment and referral settings. To move this measure to practice, there must be direct evidence for the benefits of crisis screening using the MCAS, such as increased treatment referral rates and uptake of such treatments, when compared to those who are not screened, and improved short and long term functional outcomes with treatment for those identified through the screening process.

Although the MCAS was specifically designed for those with ASD, future research could consider adapting the MCAS for other pediatric populations since, to our knowledge, no crisis measures exist for youth without ASD. Section 1, which asks parents to rate the severity of a variety of mental health problems, is the only section that may require modification depending on behaviors specific to other populations. For Section 3, there is no reason to suspect that individual items would function differently among those without ASD. DIF testing, described above, should be employed to confirm or deny this hypothesis.



Chapter 5: Table 1, Pre-post change in Family Experiences Interview Schedule (FEIS) item scores

FEIS Items	Pre		Post	
	Item Mean	% Some/All that was needed	Item Mean	% Some/All that was needed
<i>Subscale 1: Involvement with professionals</i>				
1. Receive enough information	2.7	59	3.0	78
2. Assistance if there was a crisis	2.4	46	2.9	72
3. Information about who to call during a crisis	2.3	43	3.2	74
4. Encourage to take an active role	2.8	63	3.3	84
5. Respond to concerns	2.6	59	3.1	76
6. Take into account ideas and opinions	2.8	60	3.2	83
7. Involve caregiver in treatment	3.1	77	3.6	89
8. Recognize Burdens	2.5	53	3.2	80
9. Regular contact with providers	3.2	82	3.5	89
<i>Subscale 2: Evaluations of client services</i>				
10. Services available were the ones that are needed	2.5	53	3.0	82
11. Express opinion	3.0	71	3.4	84
12. Choose between service options	2.2	37	2.8	63
13. Choose between different providers	2.5	47	2.7	58
14. Convenient to use services	2.6	49	3.2	79
15. Services flexible enough to meet needs	2.7	67	3.2	80
16. Satisfied with services	2.6	57	3.0	75
<i>Subscale 3: Response to family members</i>				
17. Respond to the wishes of the family	2.5	52	5.9	71
18. Say about services needed	2.7	61	3.3	82

19. Satisfied with role in treatment	2.8	63	3.3	86
20. Available help on nights/weekends	1.9	27	2.9	61

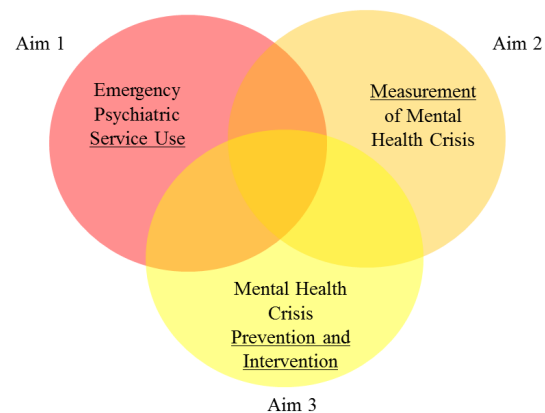
Chapter 5: Table 2, Changes in Mental Health Outcomes and Caregiver Service Experiences					
Variable	Pre-Test	Post-Test	Effect Size ( <i>d</i> )	Test statistic	p-value
<i>FEIS (Mean)</i>					
Involvement with professionals	24.5	29.1	.67	T=5.44	<.001
Evaluations of client services	18.1	21.4	.59	T=5.81	<.001
Response to family members	10.1	12.3	.67	T=5.73	<.001
Total Score	52.8	62.8	.70	T=6.12	<.001
<i>ABC (Mean)</i>					
Hyperactivity	26.6	19.8	.58	T=6.01	<.001
Irritability	25.1	18.9	.62	T=5.94	<.001
Lethargy	15.7	11.0	.56	T=4.90	<.001

Chapter: Table 3, Changes Urgent Psychiatric Service Use				
Variable	Pre-Test	Post-Test	Test statistic	p-value
<i>Psychiatric Hospitalizations (Mean)</i>	.37	.15	Z=2.60	<.01
<i>Emergency Department Visits (Mean)</i>	.69	.27	Z=2.90	<.01

## CHAPTER 6: SUMMARY AND FUTURE DIRECTIONS

The goal of this dissertation was to shed light on mental health crises among youth with ASD using the tripartite approach shown in Figure 1. This body of work revealed several important themes, including: 1) the elevated prevalence of mental health crises; 2) interplay between outpatient and inpatient services; 3) the utility of the MCAS as a novel research tool; and, 4) the potential of the START program to prevent mental health crises. Limitations to this work and avenues for future research are discussed.

Figure 1: Tripartite Approach to Mental Health Crisis



The most important theme of this dissertation was the prevalence of mental health crises was high. This can be seen in Study 1, where youth with ASD were at increased risk of visiting the ED for psychiatric purposes, and Study 2, where the prevalence of crises was nearly 40%. There are several reasons why crises are elevated among this population. The most important reason is the presence of dangerous mental health symptoms - such as aggression, self-injury, and elopement - frequently accompany ASD. This suggests the core features of ASD may themselves be an intrinsic diathesis for crisis. The complex interactions between ASD symptoms, cognitive features of ASD (e.g., intellectual disability, sensory perception), and common environmental stressors among this population (e.g., bullying, parental stress) may further exacerbate the potential for crises. Further work is required to better understand these relationships to inform prevention and intervention strategies.

It should be recognized that an inherent limitation of the insurance claims-based research in Study 1 is the ability to determine the urgency of as well as the true reason for an ED visit. Previous research has shown that many of these visits could be handled in a less restrictive environment, suggesting not all ED visits for mental health purposes are truly crises<sup>83</sup>. Future research could consider employing the MCAS in the ED to estimate the proportion of ED visits that are due to mental health crises and those that can be managed in the outpatient setting. Use of the MCAS in the ED will also help reduce visit misclassification by changing Section 2 to identify the principle psychiatric problem that led to the ED visit, rather than the most dangerous behavior. This is important since there is currently no gold standard as to what diagnosis or combination of such should be used to identify visits that are psychiatric in nature or simply reflect a child's psychiatric history.

This dissertation also raises questions about how parents manage crises. Data from Aim 1 suggests that parents may use the ED to manage these events, which is suboptimal due to the limited resources available in this setting. For instance, over 60% of child and adolescents psychiatrists across the US felt ED providers could not manage a child with ASD experiencing a crisis in a developmentally appropriate manner<sup>105</sup>. Use of the ED provides a very limited picture of crisis management, however, since most parents' manage these events themselves. For instance, 70% parents with a child in crisis in Study 2 did not use the ED or any urgent mental health service, including the ED, hospital or 911/the police, to assist in managing their child's behavior (data not reported here). These data speak to the urgent need for supporting these

families in their natural setting and further research on the strategies as well as outcomes related to the current strategies parents use to manage crises.

Use of the ED for mental health purposes has been linked to problems with access to outpatient care; although, the evidence for this connection has been mixed<sup>83,183</sup>. Findings from Aim 1 did not support the notion that increased use of the ED was simply due to decreased access to outpatient care. In fact, findings were in the opposite direction, such that those with ASD who visited the ED actually had increased outpatient mental healthcare both before and after their ED visit when compared to control groups who had substantially less psychiatric ED use. One explanation for this counterintuitive finding is outpatient providers may actually recommend families use the ED for urgent psychiatric management due to the lack of supports available to the provider. This hypothesis is supported by a national survey that found child psychiatrists have diminished access to external resources, such as other mental health professionals and psychiatric crisis evaluation centers, for children with ASD experiencing a mental health crisis<sup>105</sup>. Multimodal treatment approaches that provide more intensive outpatient options, such as respite and in-home behavior supports, than those available to a psychiatrist during a routine 15-minute appointment may be required to prevent psychiatric ED visits and crises in general. Results from the START program in Aim 3 hold such promise.

It should be recognized that the claims data available for Study 1 do not provide insight into the quality of care received. This is critical since numerous studies have reported suboptimal quality of mental healthcare provided to youth with ASD, which may be due to the lack of evidenced-based treatments available to these providers<sup>18,184,185</sup>. Future research should, therefore, examine

the effects of quality, rather than simply quantity, of outpatient care on psychiatric ED use. Investigating the effects of mental health treatments reducing urgent psychiatric service use is another important, yet understudied, area of research among youth in general.

Data from the MCAS in Study 2 provide a unique perspective regarding mental health. Previous parent-reported instruments yield little insight into the dangerousness of the child's behavior since they consider severity (e.g., mild, moderate, or severe) from a single dimension. This approach is subject to information biases since what constitutes a "mild" vs. "severe" disorder is likely a function of characteristics beyond the child's behavior (e.g., parental stress, socioeconomic status). The MCAS, on the other hand, utilizes latent variable techniques to minimize information bias by capturing the underlying and unobserved severity of the behavior through multiple indicators. By modeling this construct across two factors, including acuity and behavioral efficacy, the MCAS also provides a greater breadth and depth concerning the operationalization of the dangerousness and management of mental health symptoms.

The MCAS provides the opportunity to generate novel lines of research. An obvious first question pertains to trajectory. This includes understanding how crises change over time, risk factors for different trajectories of crises, and if there are particular subpopulations that remain in crisis overtime or if there are others who have brief/remitting crises. A second important question pertains to risk factors for crisis, such as child age and household income. A longitudinal design is needed to fully answer these questions since the temporal relationship, where risk precedes outcome, must be clear.

Research is currently being undertaken from a cross-sectional perspective to inform future longitudinal studies of crises. Preliminary data (not reported here) show that 25% and 11% of parents reported anxiety and physical aggression as the behaviors that were the most dangerous, respectively. Interestingly, the proportion of crises among those who selected anxiety as the most dangerous behavior was very low (4%), whereas more than half (56%) of those who selected aggression as the most dangerous behavior were in crisis. Also interesting, and concerning, was 20% of families who met the cutoff for crisis were not receiving any outpatient mental health treatment for their child. Parents who did not have a college degree had higher crisis scores than those with a postgraduate education and older youth had slightly lower crisis scores than younger children.

Applying the MCAS to non-ASD populations, particularly for clinical use, is an important next step in research. For instance, suicide and deaths due to opioid use have been skyrocketing over the last decade. The MCAS may be able to identify these individuals early, with the hopes of moving them to treatment, before a tragic outcome takes place. Other applications of the MCAS include assisting ED providers when making difficult decisions concerning discharge to a psychiatric hospital, informing clinical decision-making when weighing the risks and benefits of starting an antipsychotic medication, aiding pediatricians when screening for mental health issues, or helping select those in greatest need for expensive mental health services that are in high demand, such as the START program. See the discussion section of Study 2 (p.72) for further details on the research that needs to occur prior to using the MCAS in clinical settings.

An important limitation that applies to each of the studies presented here is the threat of selection bias. For Study 1, information about the employer-sponsored health insurance firms that participate in the MarketScan database was unavailable. There was also limited demographic information about the participants. Knowing little about the individuals enrolled in the MarketScan database makes it difficult to understand how different the study population was from the target population: privately-insured children in the US. Furthermore, Study 2 suffered from two levels of selection bias: 1) parents participating in IAN have a higher level of education and are more likely to be Caucasian compared to parents raising a child with ASD in the US<sup>186</sup>; and, 2) the survey response rate was very low (10%). For Study 3, the sites that participated were selected due to ease of study administration, and thus are not representative of the START programs, and the individuals they serve, across the US.

Data to address selection bias were only available to Study 2. This is because baseline information, such as parental educational status and child mental health, were available on all IAN enrollees. Having baseline data provided the opportunity to adjust for differences between respondents and non-respondents via inverse probability of treatment weights (IPTW). Preliminary data (not reported here) show that those who participated in Study 2 had greater mental health issues and autism severity than the broader non-respondents. After applying the IPTWs, the prevalence of crisis in Study 2 fell from 39% to 31%. Although the prevalence of crisis was still quite high and very clinically relevant after applying the IPTW, the substantial reduction in the prevalence of crises highlights the importance of addressing selection effects.



The third and final study provides a solution to the high rates of psychiatric ED use and mental health crisis among youth with ASD: the START program. A 40% mean reduction in both hospitalizations and psychiatric ED visits was observed among START enrollees. Reduction of urgent psychiatric service use may be related to the availability of supports during a crisis or on nights/weekends (see Table 1 of Study 3). To provide causal evidence of crisis support in reducing psychiatric ED visits and/or psychiatric hospitalizations, future research should explore the role of START crisis supports as mediator of urgent psychiatric service use.

Findings regarding the START program in Study 3 imply this program may be able to reduce mental health crises. This is suggested by two lines of evidence. First, START improved the irritability and hyperactivity of the service recipient. This finding is critical since mental health symptoms, particularly externalizing problems such as aggression and dangerous impulsivity, are commonly reported as the principle behaviors that lead to a crisis. Second, START improved the caregiver's involvement in their dependent's care. Increasing the role of the caregiver will likely lead to boosting the number of strategies they have at their disposal when their dependent is experiencing an acute mental health event. START will also help the caregiver develop preventive strategies to reduce the occurrence of crises as well as enhance their connection with providers when immediate intervention is needed. Taken together, future research could consider using the MCAS as an outcome measure in prospective studies of START.

In sum, this dissertation provides an important first step towards understanding mental health crises. Although some conclusions are presented, in many ways this work opens up more questions than it does when providing answers. I view that as a success given how little we know

about crisis. It is my hope that the research presented here will spawn further fruitful investigations that will ultimately lead to improving the life of individuals with acute mental health needs and the individuals who care for them.

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## Appendix 1: IRB Approval for Aim 1



FWA #00000287

### Institutional Review Board Office

615 N. Wolfe Street / Room E1100  
Baltimore, Maryland 21205-2179  
Phone: 410-955-3193  
Toll Free: 1-888-262-3242  
Fax: 410-502-0584  
Email: [jhsph.irboffice@jhu.edu](mailto:jhsph.irboffice@jhu.edu)  
Website: [www.jhsph.edu/irb](http://www.jhsph.edu/irb)

### NOT HUMAN SUBJECTS RESEARCH DETERMINATION NOTICE

**Date:** March 31, 2015

**To:** Elizabeth Stuart, PhD  
(Luther Kalb)  
Department of Mental Health

**Re:** **Study Title:** "Predictors of psychiatric emergency department use among youth with ASD"  
**IRB No:** 00006349

The JHSPH IRB reviewed the above-referenced new application on **March 30, 2015**. We have determined that the proposed activity described in your application will use de-identified data to undertake an analysis of the use of psychiatric emergency department visits by children with autism spectrum disorders. Thus, the proposed activity does not qualify as human subjects research as defined by DHHS regulations 45 CFR 46.102, and does not require IRB oversight.

You are responsible for notifying the JHSPH IRB of any future changes that might involve human subjects and require IRB oversight.

If you have any questions regarding this action, please contact the JHSPH IRB Office at (410) 955-3193 or via email at [jhsph.irboffice@jhu.edu](mailto:jhsph.irboffice@jhu.edu).

ES/teb

## Appendix 2: IRB Approved Consent Form for Aim 2



Date: May 29, 2015  
Principal Investigator: Roma A. Vasa, MD  
Application No.: NA\_00093205

If you are using Epic for this study, fax a copy of the signed consent form to 410-367-7382.

Patient I.D. Plate

### **RESEARCH PARTICIPANT INFORMED CONSENT AND PRIVACY AUTHORIZATION FORM**

**Protocol Title:** Psychiatric Crisis among Youth and Transition Age Adults with Autism Spectrum Disorder

**Application No.:** NA\_00093205

**Sponsor:** Autism Speaks

**Principal Investigator:** Dr. Roma Vasa, MD  
3901 Greenspring Ave  
Baltimore, MD 21211  
Phone: 443-923-2643  
Fax: 443-923-7638

#### **1. What you should know about this study:**

- You are being asked to join a research study. This consent form explains the research study and your part in the study.
- Please read it carefully and take as much time as you need.
- Ask your study doctor or the study team to explain any words or information in this informed consent that you do not understand.
- You are a volunteer. If you join the study, you can change your mind later. You can decide not to take part or you can quit at any time. There will be no penalty or loss of benefits if you decide to quit the study.
- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to be in the study.
- If you receive routine medical treatment (including medical or laboratory tests) in the study or if you are taking part in the study at the Clinical Research Unit, information about your research study participation will be included in your medical record, which is used throughout Johns Hopkins. Doctors outside of Johns Hopkins may not have access to this information. You can ask the research team to send this information to any of your doctors.
- When Johns Hopkins is used in this consent form, it includes The Johns Hopkins University, The Johns Hopkins Hospital, Johns Hopkins Bayview Medical Center, Howard County General Hospital, Johns Hopkins Community Physicians, Suburban Hospital, Sibley Memorial Hospital and All Children's Hospital.

### Appendix 3: IRB Approval for Aim 3



FWA #00000287

#### JHSPH Institutional Review Board Office

615 N. Wolfe Street / Suite E1100  
Baltimore, Maryland 21205  
Office Phone: (410) 955-3193  
Toll Free: 1-888-262-3242  
Fax Number: (410) 502-0584  
E-mail Address: [jhsph.irboffice@jhu.edu](mailto:jhsph.irboffice@jhu.edu)  
Website: [www.jhsph.edu/irb](http://www.jhsph.edu/irb)

#### NOT HUMAN SUBJECTS RESEARCH DETERMINATION NOTICE

Date: August 26, 2014

To: Elizabeth Stuart, PhD  
(Luther Kalb)  
Department of Mental Health

Re: Study Title: "Effects of Respite Services on Psychiatric Hospitalization among  
Individuals with a Dual Diagnosis: Results from the National START Program"  
IRB No: 00005926

The JHSPH IRB reviewed the above-referenced new application on **August 22, 2014**. We have determined that the proposed activity described in your application will involve the use of de-identified data to undertake a secondary analysis examining the effect of respite services on hospitalizations among persons with dual diagnoses. The investigators were not involved in the original data collection. Thus, the proposed activity does not qualify as human subjects research as defined by DHHS regulations 45 CFR 46.102, and does not require IRB oversight.

You are responsible for notifying the JHSPH IRB of any future changes that might involve human subjects and require IRB oversight.

If you have any questions regarding this action, please contact the JHSPH IRB Office at (410) 955-3193 or via email at [jhsph.irboffice@jhu.edu](mailto:jhsph.irboffice@jhu.edu).

ES/teb

## Appendix 4: CITI Ethics Training Certificate

### COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI)

#### HUMAN RESEARCH CURRICULUM COMPLETION REPORT

Printed on 06/10/2014

**LEARNER** luther kalb (ID: 745881)  
**PHONE** 443 910 0866  
**INSTITUTION** Johns Hopkins Bloomberg School of Public Health  
**EXPIRATION DATE** 06/09/2019

**BIOMEDICAL RESEARCH INVESTIGATORS :** This Learner group is mandatory for all Principal Investigators, Co-Investigators, Student Investigators and Study Staff

**COURSE/STAGE:** Refresher Course/2  
**PASSED ON:** 06/10/2014  
**REFERENCE ID:** 12163364

REQUIRED MODULES	DATE COMPLETED	SCORE
Blomed Refresher 2 - Instructions	06/10/14	No Quiz
Blomed Refresher 2 - History and Ethical Principles	06/10/14	3/3 (100%)
Blomed Refresher 2 - Regulations and Process	06/10/14	2/2 (100%)
Blomed Refresher 2 - Informed Consent	06/10/14	2/3 (67%)
Blomed Refresher 2 - SBR Methodologies in Biomedical Research	06/10/14	4/4 (100%)
Blomed Refresher 2 - Genetics Research	06/10/14	2/2 (100%)
Blomed Refresher 2 - Records-Based Research	06/10/14	1/3 (33%)
Blomed Refresher 2 - Research Involving Vulnerable Subjects	06/10/14	1/1 (100%)
Blomed Refresher 2 - Vulnerable Subjects - Prisoners	06/10/14	1/2 (50%)
Blomed Refresher 2 - Vulnerable Subjects - Children	06/10/14	1/3 (33%)
Blomed Refresher 2 - Vulnerable Subjects - Pregnant Women, Human Fetuses, Neonates	06/10/14	2/2 (100%)
Blomed Refresher 2 - FDA-Regulated Research	06/10/14	3/3 (100%)
Blomed Refresher 2 - HIPAA and Human Subjects Research	06/10/14	4/5 (80%)
Blomed Refresher 2 - Conflicts of Interest in Research Involving Human Subjects	06/10/14	3/3 (100%)
How to Complete the CITI Refresher Course and Receive a Completion Report	06/10/14	No Quiz

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI Program participating institution or be a paid Independent Learner. Falsified information and unauthorized use of the CITI Program course site is unethical, and may be considered research misconduct by your institution.

Paul Braunschweiler Ph.D.  
Professor, University of Miami  
Director Office of Research Education  
CITI Program Course Coordinator

## **Appendix 5: Status of Dissertation Manuscripts**

Study 1: Characteristics of Psychiatric Emergency Department Use among Privately Insured Adolescents with Autism Spectrum Disorder

This manuscript has been accepted with revisions by the journal of *Autism* (Sage Publishers)

Study 2: Psychometric Characteristics of the Mental Health Assessment Scale

This manuscript has been published in *the Journal of Child Psychology and Psychiatry* (Wiley Publishers; doi: 10.1111/jcpp.12748).

Study 3: Improvement in Mental Health Outcomes and Caregiver Service Experiences Associated with the START Program is currently under review in the *American Journal of Intellectual and Developmental Disabilities* (American Association on Intellectual and Developmental Disabilities).



## Curriculum Vitae

### Education

- 2017 PhD Johns Hopkins Bloomberg School of Public Health  
Department of Mental Health  
Dissertation: Mental Health Crises in Youth with Autism Spectrum Disorder  
Advisor: Elizabeth Stuart, PhD
- 2008 MHS Johns Hopkins Bloomberg School of Public Health  
Department of Mental Health
- 2006 BA University of Baltimore  
Department of Psychology

### Professional Experience

- 2017 *Research Scientist*, Center for Autism and Related Disorders (CARD) and Department of Neuropsychology, Kennedy Krieger Institute.
- 2013 *Research Manager*, CARD and Department of Medical Informatics, Kennedy Krieger Institute.
- 2010 *Research Coordinator III*, CARD and Department of Medical Informatics, Kennedy Krieger Institute
- 2008 *Research Coordinator I*, CARD, Kennedy Krieger Institute.
- 2006 *Discharge Coordinator*, Child and Adolescent Neuropsychiatric Unit, Sheppard Pratt Health System

2004        *Mental Health Worker*, Child and Adolescent Neuropsychiatric Unit, Sheppard  
Pratt Health System

Teaching and Training Experience

2016        *Teaching Assistant*, Introduction to Mental Health Services, Johns Hopkins  
Bloomberg School of Public Health

2015        *Research Assistant*, Supervisor: Colleen Barry, PhD; Professor and Chair,  
Department of Health Policy and Administration. Johns Hopkins Bloomberg  
School of Public Health.

2015        *Teaching Assistant*, Psychiatric Epidemiology, Johns Hopkins Bloomberg School  
of Public Health

2015        *Trainee*, Center for Mental Health and Addiction Policy Research, Johns Hopkins  
Bloomberg School of Public Health

2014        *Research Assistant*, Supervisor: Elizabeth Letourneau, PhD, Professor and  
Director of the Moore Center for Prevention of Child Sexual Abuse. Johns  
Hopkins School of Public Health.

2014        *Instructor*, Introduction to Statistics, Summer Research Training Program for  
Child Psychiatry Residents, Johns Hopkins University

2013        *Research Assistant*, Supervisor: Alden Gross, PhD, MHS; Assistant Professor,  
Department of Epidemiology. Johns Hopkins Bloomberg School of Public Health.

- 2013        *Intern*, Biostatistics Center for Clinical and Translational Research, Johns Hopkins Bloomberg School of Public Health
- 2010        *Instructor*, Genetics, Health, and Lifestyle, Department of Occupational Therapy, Towson University

#### Awards and Recognitions

- 2016        Morton Kramer Award for Excellence in Epidemiology and Biostatistics, Johns Hopkins School of Public Health
- 2016        NIMH New Investigators Workshop, Selected Invitee
- 2014        Wendy Klag Center for Autism and Developmental Disabilities Scholar
- 2013        T-32 NIMH Children Mental Health Services Training Pre-doctoral Fellowship
- 2006        Cum Laude, University of Baltimore
- 2004        Deans Scholarship, University of Baltimore

#### Peer-reviewed, Scientific Journal Publications

1. **Kalb, L.**, Stuart, E., Mandell, D., Olfson, M., & Vasa, R. Management of Mental Health Crises among Children with and without Autism Spectrum Disorder: A National Survey of Child Psychiatrists. *Psychiatric Services* (in press).
2. **Kalb, L.**, Hagopian, L., Gross, A., & Vasa, R. Psychometric Characteristics of the Mental Health Crisis Assessment Scale in Youth with Autism Spectrum Disorder. *Journal of Child Psychology and Psychiatry* (in press).

3. Stuart, E., McGinty, E., **Kalb, L.**, et al. (2017). Increased Service Use and Spending among Children with Autism Spectrum Disorders Associated with Federal Parity Law. *Health Affairs* (36)2.
4. **Kalb, L.**, Beasley, J., Klein, A., Hinton, J., & Charlot, J. (2016). Psychiatric Hospitalization among Individuals with Intellectual Disability Referred to the START Crisis Intervention and Prevention Program. *Journal of Intellectual Disability Research* 60(12), 1153-1164
5. **Kalb, L.**, Vasa, R., Goldstein, M., Ballard, E., & Wilcox, H. (2016). Epidemiology of Injury-related Emergency Department Visits among Youth with Autism Spectrum Disorder. *Journal of Autism and Developmental Disabilities* 45: 2756.
6. Ballard, E., **Kalb, L.**, Vasa, R., Goldstein, M., & Wilcox, H. (2015). Self-harm, Assault, and Undetermined Intent Injuries among Pediatric Emergency Department Visits *Pediatric Emergency Care* 31(12), 813-818.
7. Vasa, R., Suskauer, S., Thorn, J., **Kalb, L.**, Grados, M., Slomine, B., & Gerring, J. (2015). Prevalence and Predictors of Affective Lability after Paediatric Traumatic Brain Injury. *Brain Injury* 29(7-8), 921-928.
8. Keefer, A., **Kalb, L.**, Vasa, R., Mazurek, M., Freedman, B., & Kanne, S. (2014). Methodological Considerations When Assessing Restricted and Repetitive Behaviors and Aggression. *Research in Autism Spectrum Disorders* 8(11), 1527-1534.
9. Bent, S., Hendren, RL., Zandi, T., Law, K., Choi, JE., Widjaja F., **Kalb, L.**, Nestle, J., & Law, P. (2014). Internet-based, randomized, controlled trial of omega-3 Fatty acids for

- hyperactivity in autism. *Journal of the American Academy of Child and Adolescent Psychiatry* 53(6), 658-666.
10. Zablotsky, B., **Kalb, L.**, Stuart, E., Freedman, B., & Vasa, R. (2014). Impact of Healthcare Experiences on Family Finances among Parents Raising a Child with an Autism Spectrum Disorder. *Psychiatric Services* 65(3): 395-398.
  11. Vasa, R., **Kalb, L.**, Freedman, B., Mazurek, M., Keefer, A., Kanne, S., & Murray, D. (2013). Age-related Differences in Anxiety among Children with Autism Spectrum Disorder. *Research in Autism Spectrum Disorders* 7 (11), 1358-1369.
  12. Wodka, E., Mathy P., & **Kalb, L.** (2013). Predictors of Phrase and Fluent Speech in Children with Autism and Severe Language-Delay. *Pediatrics* 131(4), 1128- 1134.
  13. Mazurek, M., Vasa, R., **Kalb, L.**, Kanne, S., Rosenberg, D., et al. (2013). Examining Relations between Anxiety, Sensory Over-Responsivity, and Gastrointestinal Problems among Children with Autism Spectrum Disorders. *Journal of Abnormal Child Psychology* 41(1), 165-176.
  14. **Kalb, L.**, Stuart, E., Freedman, B., Zablotsky, B., & Vasa, R. (2012). Psychiatric-related Emergency Department Visits among Children with Autism Spectrum Disorders. *Pediatric Emergency Care* 28 (12), 1269-1276
  15. Landa, R. & **Kalb, L.** (2012). Long-Term Outcomes of Toddlers with Autism Spectrum Disorders Exposed to Short-term Intervention. *Pediatrics* 130 (Supplement 2), S186-S190.

16. **Kalb, L.**, Freedman, B., Foster, C., Menon, D., Kisfy, L., Landa, R., & Law, P (2012). Determinants of Appointment Attendance at an Outpatient Pediatric Autism Clinic. *Journal of Developmental and Behavioral Pediatrics* 33 (9), 685-697.
17. **Kalb, L.**, Cohen, C., Lehmann, H., & Law, P. Survey Nonresponse in an Internet-Mediated, Longitudinal Autism Research Study (2012). *Journal of the American Medical Informatics Association* 19 (4), 668-673.
18. Freedman, B., **Kalb, L.**, Zablotsky, B., & Stuart, E (2012). Relationship Status among Parents of Child with an Autism Spectrum Disorder: A Population-Based Study. *Journal of Autism and Developmental Disabilities* 42 (4), 539-548.
19. Zayat, M., **Kalb, L.**, & Wodka, E (2011). Performance Pattern Differences on Measures of Verbal Intelligence in Children with Autism Spectrum Disorders and Attention Deficit-Hyperactivity Disorder. *Journal of Autism and Developmental Disabilities* 41 (12), 1743-1747.
20. **Kalb, L.**, Law, K., Landa, R., & Law, P. (2010). Onset Patterns Prior to 36 Months in Autism Spectrum Disorders. *Journal of Autism and Developmental Disabilities* 40 (11), 1389-1402.

#### Under Review

21. **Kalb, L.**, Stuart, E., & Vasa, R. Psychiatric Emergency Department Use and Continuity of Care among Privately Insured Adolescents with and without Autism Spectrum Disorder. *Autism* (under review).

22. **Kalb, L.**, Beasley, J., Caoili, A., & Klein, A. Improvement in Mental Health Outcomes and Caregiver Service Experiences Associated with the START Program. *American Journal of Intellectual and Developmental Disabilities* (under review).

#### Other Publications

1. Foster, C., & **Kalb, L.** (2013). Book Chapter: Chapter 9: Presenting your research findings. *A Writer's Toolkit for Occupational Therapy and Health Care Professionals*. American Occupational Therapy Association (AOTA) Press.
2. **Kalb, L.** (2011). Book Review: Behavioural Concerns & Autistic Spectrum Disorders: Explanations and Strategies for Change, Clements & Ewa Zarkowska. *Journal of Autism and Developmental Disabilities* 41 (2), 254-255.
3. Kaplan, D., Berthod, S., **Kalb, L.**, et al. (2007). The Establishment of a Psychiatric Inpatient Unit for Children and Adolescents with Developmental Disabilities. *The National Association for Developmental Disabilities Bulletin* Volume X, 4(4).

Citation Index: <https://scholar.google.com/citations?user=oYk0lE4AAAAJ&hl=en>

#### Scientific Grants

1. Evaluation of the START Crisis Intervention and Prevention Program  
National Institute for Child Health and Development (NICHD)  
F-31 Ruth L Kirschstein National Research Service Award  
Funding Amount: \$125,000 (2016-2017)

Role: Principal Investigator

2. Effects of Federal Mental Health Parity on Psychiatric Emergency Department Use among Children with ASD

Johns Hopkins Bloomberg School of Public Health

Wendy Klag Center for Autism & Developmental Disabilities

Funding Amount: \$5,000 (2015-2016)

Role: Principal Investigator

3. Improving Treatment of Psychiatric Crisis among Children with ASD

Autism Speaks Treatment Grant (2014-2016)

Funding Amount: \$120,000 (15% effort)

Role: Co-Principal Investigator

PI: Roma Vasa, MD – Associate Professor, Johns Hopkins University

#### Ad-Hoc Reviewer Experience

*BMJ Open, BMC Psychiatry, Autism: International Journal of Research and Practice, European Journal of Child Psychiatry and Psychology, Journal of Child Psychology and Psychiatry, Journal of Pediatric Emergency Care, Research in Developmental Disabilities, Pediatrics, Journal of Autism and Developmental Disabilities, Journal of Attention Disorders*

#### Abstracts

1. Gross, A., **Kalb, L.**, Young, G., Stuart, E., et al. (2016). Development and Validation of a Harmonized Scale of Autism Symptom Severity Across ADOS Modules 1 and 2: A BSRC Study. *International Meeting for Autism Research (IMFAR)*. Baltimore, MD.



2. Keefer, A., **Kalb, L.**, Vasa, R., et al. (2014). Associations between Aggression and Stereotypic Movements in Children with Autism Spectrum Disorder: A Multi-Method, Multi-Informant Study. *IMFAR*. Atlanta, GA.
3. Wodka, E., Mathy, P., & **Kalb, L.** (2013). Predictors of Speech in Severely Language-Delayed Children with Autism. *Annual Meeting of the International Neuropsychological Society*. Waikoloa, Hawaii.
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